

**Parents with Learning Disabilities: Perception of Assumptions  
made by Health and Social Care Professionals about their Right  
and Ability to be a Parent.**

**Joanna Rose**

A thesis submitted in partial fulfilment of the requirements of  
the University of Lincoln for the degree of Doctor of Clinical Psychology

**2013**

## **Thesis Abstract**

The number of people with learning disabilities (LD) who become parents is rapidly increasing, as opportunities widen for people with LD to participate in all aspects of society. However, parents with LD continue to face negative attitudes and potential discrimination from both professionals and the wider community, based on erroneous assumptions, stemming from eugenic principles.

This thesis investigated the experiences of parents with LD, with regard to the assumptions they encounter or perceive from the professionals who support them. Although previous research has established the continued existence of negative attitudes amongst professionals, no research has considered the awareness and impact of such assumptions from the perspective of the parents themselves.

Thematic analysis was deemed an appropriate methodology to address the gap in qualitative research with this population, a method which allowed investigation of parents' experiences while providing the flexibility to accommodate the particular abilities of people with LD. Semi-structured interviews were conducted with ten parents with LD, whose children remained living at home with them following an assessment of their parenting.

Following analysis of interview transcripts, four overarching themes were established, based on their frequency and importance for participants. In the first super-ordinate theme, parents attributed a number of negative attitudes

to professionals, at times based on directly expressed assumptions by professionals, but most often inferred without direct experience. A second related, but distinct theme was parents' experiences of treatment by professionals. The instances of negative treatment parents described may have led to the attribution of assumptions by professionals. However, it is equally possible that parents' pre-conception of professional assumptions influenced the way they experienced professional treatment. A third theme related to the impact of both inferred professional assumptions and treatment on parents, particularly in terms of emotional consequences and willingness to engage. Given that parents were all aware of negative assumptions, a final theme considered the extent to which parents internalised negative assumptions and applied them to themselves. Additional themes in an extended paper highlighted examples of good practice, leading to a number of recommendations for professionals working with parents with LD. For all ten parents, the importance of constructive and empowering professional relationships, as opposed to paternalistic and disempowering treatment based on outdated assumptions was emphasised.

These results represent the first exploration of parents with LD's awareness and experience of negative assumptions and stigma, and have clear implications in terms of professional approaches to working with parents with LD.

## **ACKNOWLEDGEMENTS**

I would like to thank Rachel Sabin-Farrell for her support, warmth and patience as a research supervisor throughout this project. I would also like to thank Anne-Marie Mensink for her kindness and support going back many years, and now for her expertise and guidance throughout my thesis. Thanks also to all of the staff working in the Community Learning Disability Teams for their welcome and encouragement. Finally, I would like to dedicate this thesis to my mum, Jackie, who is, and has been, a constant source of inspiration, and whose love, support (and expert proofreading!) have made it possible for me to get there in the end.

## **Statement of Contribution**

During the completion of the following research, the majority of responsibility with regard to project design, application for ethical approval, reviewing the relevant literature, recruitment of participants, collection and transcription of data, data analysis and presentation of results, was held by the trainee clinical psychologist.

Advice regarding application for ethical approval and project design was provided by Dr Rachel Sabin-Farrell (Research Supervisor). At a later stage, advice was given by Dr Nima Moghaddam (Research Supervisor) with regard to data analysis and presentation of results. Finally, Dr Anne-Marie Mensink provided assistance with access to and recruitment of participants, as well as advice pertaining to the adaptation of project design to meet the needs of participants with learning disabilities.

## **CONTENTS**

<u>Chapter</u>	<u>Section</u>		<u>Page</u>
<b><u>Systematic Review</u></b>			9
		Abstract	11
		Introduction	12
		Method	21
		Results	23
		Discussion	37
		References	44
<b><u>Journal Paper</u></b>			51
		Abstract	53
		Introduction	54
		Method	58
		Results	63
		Discussion	79
		References	89
<b><u>Extended Paper</u></b>			
<u>Introduction</u>	<b>1.1</b>	<b>Background Information</b>	96
	1.1.1	Learning Disability (LD) definition	96
	1.1.2	Learning Disability terminology	98
	1.1.3	Prevalence of parents with LD	99
	<b>1.2</b>	<b>Perspectives about people with LD as parents</b>	99
	1.2.1	Historical Perspectives	99
	1.2.2	Inclusion movement and current government policy	101

	1.2.3	Myths about parents with LD	103
	1.2.4	Evidence contradicting myths about parents with LD	103
	1.2.5	Professional attitudes towards sexuality and parenting in people with LD	106
	<b>1.3</b>	<b>Discrimination against parents with LD</b>	108
	1.3.1	Outcomes of Child Protection proceedings	109
	1.3.2	Stigma in people with LD	111
	1.3.3	Theory of Planned Behaviour	113
	1.3.4	Treatment of parents with LD by professionals	114
	<b>1.4</b>	<b>Assessing parents with LD</b>	118
	1.4.1	Factors influencing parenting adequacy in people with LD	118
	1.4.2	Assessment practice for parents with LD	121
	1.4.3	Regional variability of service provision	122
	<b>1.5</b>	<b>Parents' views of services</b>	123
<u>Methodology</u>	2.1	Thematic Analysis	124
	2.2	Inclusion Criteria	126
	2.3	Participant Synopses	126
	2.4	Qualitative methods with people with LD	129
	2.5	Ethical Considerations	130
	2.6	Epistemology – Critical Realism	132
	2.7	Reliability and validity in qualitative research	133
<u>Results</u>	3.1	Overview of Extended Results	135
	3.2	Additional Themes relating to Super-ordinate theme 2	137
	3.3	Additional Themes relating to Super-ordinate theme 3	145
	3.4	Additional Themes relating to Super-ordinate theme 4	145
<u>Discussion</u>	4.1	Extended discussion of main findings	147
	4.2	Discussion of additional themes	148

	4.3	Extended Critique	150
	4.4	Transferability of Findings	152
	4.5	Implications and Recommendations	153
	4.6	Good Practice Guidelines	154
<u>Critical Reflection</u>	5		156
<b>References</b>			164
<b>Appendices</b>			185

## LIST OF FIGURES/ TABLES

<u>Section</u>	<u>Table/ Figure</u>	<u>Title</u>	<u>Page</u>
<u>Systematic Review</u>	Table 1	Newcastle-Ottowa Scale Scores	24
	Table 2	Studies investigating impact of personal characteristics on parental adequacy	28
	Table 3	Studies investigating impact of partner and child characteristics on parental adequacy	32
	Table 4	Studies investigating impact of social support on parental adequacy	35
	Figure 1	Model of multiple determinants of parenting	16
	Figure 2	Model of determinants of parenting in LD	17
<u>Journal Article</u>	Table 5	Demographic information of participants	60
	Figure 3	Thematic Map	64
	Figure 4	Cycle of Reinforcement	80
<u>Extended Paper</u>	Figure 5	Extended Thematic Map	136



## LIST OF APPENDICES

<b><u>Appendix</u></b>	<b><u>Description</u></b>	<b><u>Page</u></b>
<b>A</b>	Selection Strategy	186
<b>B</b>	NOS Scoring Guidelines	187
<b>C</b>	Information sheet for professionals	188
<b>D</b>	Interview Schedule	191
<b>E</b>	Ethical Approval	195
<b>F</b>	Accessible Information Sheet for participants	213
<b>G</b>	Participant Consent Form	216
<b>H</b>	Interview extract with codes	218
<b>I</b>	Example of data extracts for a single code	229

# **Systematic Literature Review**

**Factors influencing parental adequacy in parents who  
have learning disabilities**

**Prepared for submission to:**

***Journal of Applied Research in Intellectual Disabilities***

## **Abstract**

*Background* - There has been a recent rapid rise in the number of parents with learning disabilities referred to services in the UK for assessment of their parenting abilities. This review aims to identify which psychosocial factors are influential in predicting the parental adequacy of parents with learning disabilities.

*Methodology* -A systematic search of peer-reviewed journals was carried out using electronic databases. In total, eight studies were identified which met the review inclusion criteria. The quality of these studies was addressed.

*Principal Findings* - There is evidence to suggest that the availability of social support is key in determining parental adequacy, however it appears that the quality rather than the quantity of support is vital. Where a partner is directly involved in parenting, partner characteristics are associated with level of risk to the child. Finally, there is mixed evidence regarding the impact of individual parent and child characteristics on the outcome of parenting for individuals with learning disabilities.

*Conclusions* - Methodological disparities between the studies make comparison of results difficult, however the limited evidence available suggests that given the particular challenges faced by parents with learning disabilities, a more complex model of determining parental adequacy is required for these parents compared to the general population. Further research is required to elucidate the nature and interactions of these factors and to address disparities in the current research base.

## **Introduction**

### *Prevalence of Parents with Learning Disabilities (LD)*

Given that parents with LD often never come into contact with services, it has proved difficult to estimate the number parents in this situation within the UK (Booth, 2000). This situation is compounded by the fact that where parents are known to services, services are often fragmented in nature and have historically kept poor records. However, a recent study published by the Department of Health (2007) estimates the number of parents with a learning disability in the UK to be between 23,000 and 250,000. What appears clear, is that the number of parents with LD being referred to learning disability services for assessment is rapidly increasing, with various authors noting an increase in referrals to Clinical Psychology Departments (e.g. Bradley, Toft & Collins, 2000), community learning disability teams (e.g. Guinea, 2001) and advocacy services (Mansell & West, 2000).

### *Definition of Learning Disabilities*

The term 'learning disability' has been defined by the Department of Health (2001) as incorporating three key factors:

- “• A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development”

(p.14)

In practical terms, in determining an individual's eligibility to access specialist LD services, this is often based on standardised intelligence scores as measured by tests such as the Wechsler Adult Intelligence Scale. Thus to be classified as having a learning disability, an individual would have an IQ of less than 70, which represents a score two standard deviations below the mean IQ of the general population (Crawford, Gray & Allan, 1995). While previous research has often used IQ to determine eligibility of participants, where this information is not available, a more social definition is applied: in these cases, participants will be included if they are in receipt of specialist health or welfare services for individuals with LD (Llewellyn, 1995).

#### *Discrimination against parents with LD*

Throughout the years, individuals with LD have faced huge challenges to be able to enjoy the same rights and freedoms as the general population, particularly with regard to sexuality and parenthood. Since the eugenics movement in the 1930's, when there was heavy pressure for people with LD to be sterilised, there has remained a pervasive assumption that those with LD do not have the right or the fundamental ability to become parents. Since then, strong evidence has been provided that people with LD can indeed be effective and loving parents (Booth & Booth, 2000) and governmental policy has promoted the rights of people with LD to be included in all aspects of society (Department of Health, 2001).

Despite this, the rate of removal of children from parents with LD is exceedingly high, with studies from the USA, Sweden and New Zealand finding that between 40 and 45% of children born to families headed by an individual with LD are removed (Accardo & Whitman, 1989; Gillberg & Geijer-Karlsson, 1983; Mirfin-Veich et al., 1999). Several authors have claimed evidence of discrimination within child protection proceedings (McConnell & Llewellyn, 2000). Booth, Booth and McConnell (2005) examined the proportion of parents with LD among a sample of child protection cases. They made up over 15% of the total cases, which given that parents with LD make up less than 1% of all parents, demonstrates a clear over-representation. While this alone could be taken as evidence purely of the lack of ability of individuals with LD to parent successfully, Nicholson (1997) demonstrated that it is easier to remove a child from parents with LD than those without, even when the level of risk is the same.

McConnell and Llewellyn (2002) claim a key reason for this is the prevalence of stereotypes pervading mental health research and practice, in particular that having a learning disability is sufficient to predict parental inadequacy (e.g. Hayman, 1990) and that it is not possible for parents with LD to overcome perceived difficulties in parenting (e.g. Levesque, 1996). With these underlying assumptions in mind, it seems crucial to provide accurate information on what factors determine the outcome for parents with LD, so that it might become a question not of whether an individual with LD can be a successful parent, but under what conditions.

### *Parenting Assessment and Parental Adequacy*

Given the increasing number of parents with LD referred to services, the need to quickly and accurately assess risk is of particular importance (McGaw, Scully & Pritchard, 2010). In practice however, the assessment of parents with LD remains inconsistent and at times insufficient (Department of Health, 2000). While this may be partly explained by the lack of available assessment tools specifically designed for parents with LD (Tarleton, Ward & Howarth, 2006), there also appears to be a lack of clarity amongst professionals as to what might constitute parental competency and what factors might influence parental outcomes.

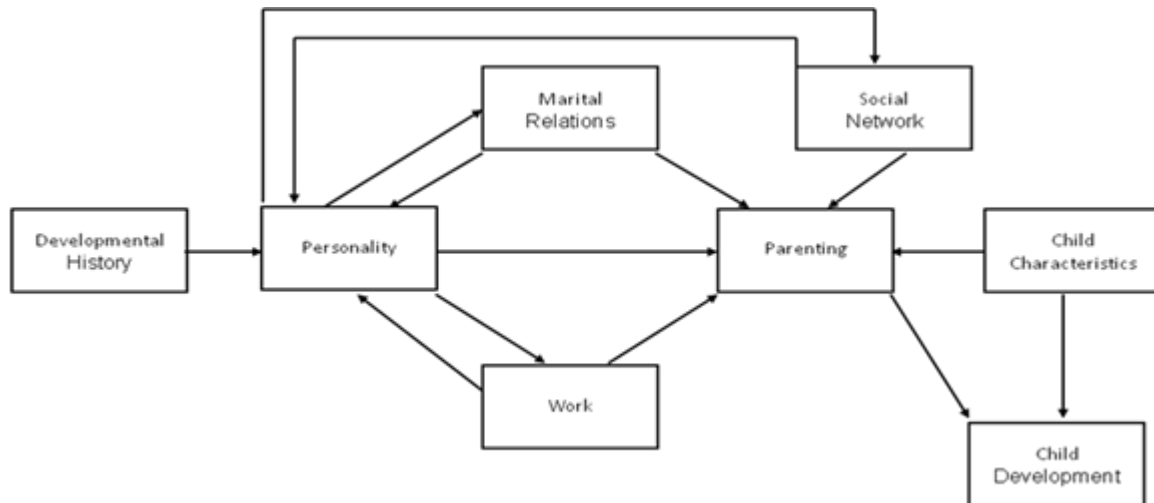
This lack of clarity extends to research into parental adequacy, which has been notoriously difficult to define (Young & Hawkins, 2005). Within literature investigating factors involved in parental adequacy in people with LD, three kinds of outcome measure are used: the first directly assesses some measure of parenting (e.g. parenting style; parent-child interactions); the second defines adequacy in terms of the presence or absence of abuse and neglect; the third judges parental success in terms of the characteristics of the child (e.g. child development or child behaviour).

### *Determinants of Parenting in the general population*

Within the general population, there have been attempts to clarify the determinants of parenting. Belsky (1984) proposed a 'multiple determinants of parenting' model, suggesting that three key domains impact on the nature and quality of parenting (See Figure 1).



Figure 1: Model of Multiple Determinants of Parenting (Belsky, 1984)

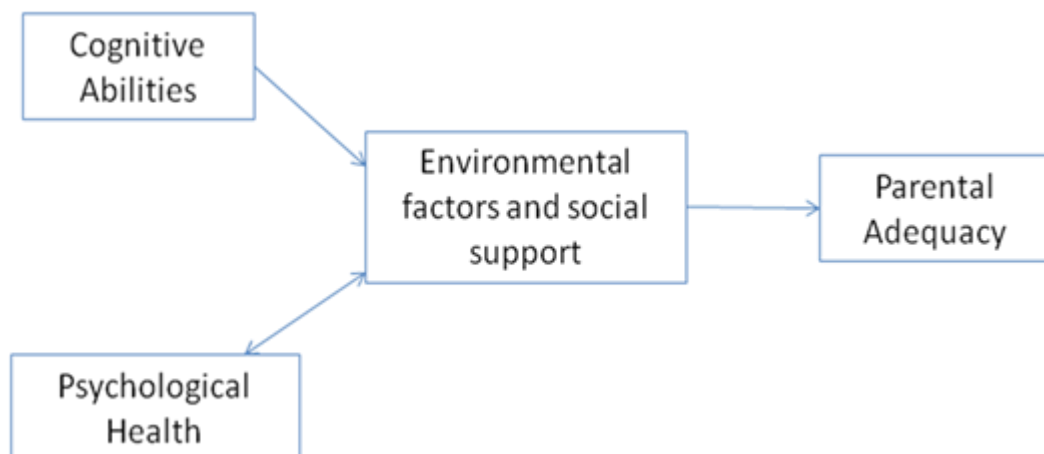


The three subsystems highlighted above address factors within the parent, within the child and within a broader social context in which the family functions. Within this interactional model, parental developmental history is assumed to influence both personality and psychological well-being, with a supportive developmental experience likely to lead to a personality capable of providing supportive parenting. Personality is shown to affect contextual support and stress, which can promote or undermine parental competence. Positive social support is posited to influence parenting both through increasing parental self-esteem and through buffering the effects of stress. Finally, the evidence suggests that rather than specific child characteristics, it is a 'goodness-of-fit' between parent and child that shapes the success of parent-child relations. Numerous authors have provided evidence to support the various determinants within Belsky's model (e.g. Belsky, Woodworth & Crnic, 1996).

### *Parental Adequacy in parents with LD*

While Belsky's (1984) model of determinants of parenting has been substantiated for the general population, there is no evidence that such a model could be generalised to a population of parents with LD. There is reason to think, given the nature of population and the particular difficulties they experience, that the model would need to be adapted for an LD population. In an effort to address this, Sterling (1998) proposed an adaptation of Belsky's (1984) model (See Figure 2). Again, the model includes three main subsystems, although the impact of child characteristics is replaced by the impact of parental cognitive function in determining parental adequacy.

Figure 2: Model of determinants of parenting in learning disabilities (Sterling, 1998)



The first system encompasses the parent's social support system, which is viewed as the primary determinant of parenting, acting as a mediator for cognitive abilities, psychological health and parenting performance. In this model, the parent's partner is not viewed as a separate source of support, being subsumed instead within the category of social support. The second system involves the psychological health of the parent, with an emphasis on the presence or absence of depression. It is suggested that the relationship between depression and social support is reciprocal: a mother experiencing symptoms of depression is less likely to seek social contact, while conversely, a lack of available social support can increase symptoms of depression. The third key element is assumed to be the cognitive ability of the parent, acting both independently (in that a parent with lower cognitive ability is assumed to display more parenting behaviours that may place a child at risk) and through its influence on a parent's level of social support.

#### *Challenges faced by parents with LD*

Parents with LD are known to face additional challenges in their parenting role, particularly with regard to a number of the factors discussed in the models above. As Belsky (1984) highlights, the role of stress has been consistently linked to parental well-being, parenting behaviour and child outcomes. Parents with LD have been shown to experience greater levels of overall stress than a comparison group of mothers with average IQ (Feldman, Leger & Walton-Allen, 1997). Additionally, parents with LD are more frequently found to be living in poverty than parents without LD (Booth

& Booth, 1994). They are more likely to come from low socio-economic backgrounds, a group which have been shown to be over-represented in child protection proceedings in their own right (Schilling et al., 1982).

People with LD are more likely to suffer from additional mental health problems compared to the general population (Cooper, Smiley, Morrison, Williamson & Allan, 2007) and it has been shown that the risk of mental health problems increases with pregnancy and parenthood (McConnell, Mayes & Llewellyn, 2008). Finally, although positive social support has been shown to impact on the success of parenthood, people with LD are often more socially isolated compared to the general population (Myers, Ager, Kerr & Myles, 1998). Mothers with LD report a higher perceived need for social support compared to mothers without LD, but a lower satisfaction with the support received, particularly in terms of community involvement and friendships (Feldman, Varghese, Ramsay & Rajska, 2002).

### *Previous Literature Review*

A review of influences on parenting ability of individuals with LD was conducted in 1993 by Dowdney and Skuse. Determinants of parenting examined at the time were limited to three areas: the intellectual level of the parent; child characteristics; and family factors.

They reported no correlation between parental IQ and parental competence, except when IQ falls below 55-60, at which point there may be a decrease in competence. However, this claim was based on only three studies (Borgman, 1969; Mickelson, 1947; Shaw & Wright, 1960), each of which, according to

Dowdney and Skuse (1993) contained such methodological flaws that their findings should not be taken 'at face value'. The impact of child characteristics had been largely ignored in research on parents with LD, other than to say that as a child progresses beyond pre-school, a parent with LD is less likely to cope and more likely to seek professional help (Accardo & Whitman, 1990). Finally, the impact of family factors was discussed, but again, in the absence of systematic investigation, evidence was limited to the fact that as family size increases, there is a greater likelihood of abuse, and a decrease in the quality of care provided.

Further issues were raised about the quality of the evidence on which predictions of parental adequacy were based at that time by Tymchuk and Andron (1992). They highlighted that much of the information came from studies at a time when the idea of people with LD becoming parents was abhorrent to many, thus introducing a clear bias to research. It is suggested that much of this research should be at least re-examined if not discarded all together (Tymchuk, Andron & Unger, 1987). In addition, the poor quality of the evidence available was emphasised, as it was largely based on small samples and generalised from parents with borderline IQ (up to 85) to represent the entire population of parents with LD.

## *Aims*

The aims of the current review, therefore, are threefold:

- 1) To investigate the psychosocial determinants of parenting in individuals with LD, bringing up-to-date the results of the Dowdney & Skuse (1993) review.
- 2) To assess the quality of this evidence in light of methodological concerns highlighted by Tymchuk and Andron (1992).
- 3) To establish whether Sterling's (1998) model of parental adequacy in individuals with LD is supported by this evidence.

## **Method**

### *Definitions*

For the purposes of the current study, parental adequacy will be defined in three ways: through any direct measure of parenting quality; through the assessment of parental risk status in terms of the occurrence or non-occurrence of abuse or neglect; and through child developmental and behavioural outcomes.

### *Inclusion/ Exclusion Criteria*

The current review includes studies conducted using quantitative methods between January 1991 and July 2011. Articles were included if they were primary research studies from peer-reviewed publications and investigated factors which influence the parental adequacy of parents with LD. Articles

referring to parent training interventions were not included for the purposes of this review and articles which utilised solely qualitative methods were also excluded.

### *Search Strategy*

Searches of major databases, including PsycInfo, MEDLINE, Embase and Amed, were conducted in July 2011. Searches focused around three main areas: parents; learning disabilities; and parental adequacy. The latter of these was defined through the previously discussed outcomes of child development, care proceedings, positive parenting practices and the presence or absence of abuse or neglect.

Searches for combinations of terms were completed<sup>1</sup>. Terms were combined using the 'AND' and 'OR' functions and keywords were auto-exploded. Additionally, searches were conducted for articles written by key authors in the field (T Booth; W Booth; Tymchuk; McGraw; Feldman; McConnell; Llewellyn) and the reference sections of key articles were checked for further relevant articles.

### *Selection (See Appendix A)*

A total of 68 articles were found using the search strategy employed above. The abstracts of each of these articles were read, and of these, 44 were

---

<sup>1</sup> Terms searched included: *parents, mothers, fathers; learning disabilities, learning difficulties, intellectual disabilities, intellectual difficulties, mental retardation, developmental disabilities, developmental difficulties, learning disorders, cognitive disabilities; outcome, risk, risk factors, child neglect, child abuse, sexual abuse, emotional abuse, physical abuse, custody, child custody, childrearing practices, childhood development, parental attitudes, mother-child interactions, language development, parenting style, parental adequacy, parenting skills, parental characteristics, child behaviour.*

discarded. The full texts of the remaining 24 articles were read and assessed for eligibility. Of these, 16 were eliminated. Reasons for elimination from the review included: the articles referred to parents who had a child with LD (n=1); the article referred to the outcomes of parent training programme (n=3); the article used purely qualitative methods (n=5); or the article examined the prevalence of factors determining parental adequacy without any measure of impact on parenting (n=8).

### *Data Abstraction*

Relevant data was extracted from each study. This included features of the study such as authors, date of publication and country of origin. Methodological features of the study, measures used and definitions of parental adequacy, as well the key findings relating to the review question were also abstracted. Finally demographic details of the participants such as numbers, age and IQ were collected where available.

## **Results**

### *Quality*

The final eight studies were all non-experimental (observational) studies. The Cochrane Non-Randomised Studies Methods Working Group recommends the use of the Newcastle-Ottawa Scale (NOS) (Wells et al., 2005) to assess the quality of such research. Since the studies included in the current review are cross-sectional in design, an adapted version of the NOS specific to cross-



sectional research has been used to assess quality (Herzog et al., 2013). The tool assesses quality across three domains (Selection, Comparability and Outcome), with a maximum possible score of 10. Table 1 provides a summary of scores (See Appendix B for scoring guidelines).

**Table 1: Newcastle Ottawa Scale Scores**

Paper no.	Author	Methodological Criteria						Quality Score	
		Selection				Comparability	Outcome		
		Sample	Sample Size	Response	Tools	Controls	Assessment	Statistical Test	
1	Keltner, Wise & Taylor, 1999	*			**	**	**	*	8
2	Ehlers-Flint, 2002				*		*	*	3
3	Feldman, Varghese, Ramsay & Rajska, 2002	*			**		*	*	5
4	McConnell, Uewellyn, Mayes, Russo & Honey, 2003	*			*	*	*	*	5
5	Aunos, Goupil, Feldman, 2004	*			*	*	**	*	6
6	McGaw, Shaw & Beckley, 2007	*		*	**		**	*	7
7	Aunos, Feldman & Goupil, 2008				**		*	*	4
8	McGaw, Scully & Pritchard, 2010	*		*	**	*	**	*	8

### *General Characteristics*

The papers making up the current literature review represent a multi-national group, with two conducted in the UK (6,8), three in Canada (3,5,7), two in the USA (1,2) and one in Australia (4). All studies employed a cross-sectional design, one of which included elements of a longitudinal design (7). Of the eight studies, only three included fathers in their participant

selection (4,6,8). Of the studies which did include fathers, they represented only 23 out of a total of 150 parents.

The majority of studies actively interviewed participants and administered measures, however one study relied solely on archived information from a file review (8). The studies varied in method of recruitment, with four recruiting from governmental agencies specific for people with LD (3,4,5,7), one from a charitable organisation for families with disabilities (2), two from specialist parenting services for individuals with LD (6,8), and one through general pre- and post-natal services (1).

There was little consistency amongst the studies in terms of how they defined parental adequacy, with one paper using a range of outcomes as a measure of parenting quality. In total, three used some direct assessment of parenting (either parenting style, parenting quality or nature of mother-child interactions), three utilised an evaluation of parental risk (either as determined by the removal of children from their parents, or by the children having been placed on the Child Protection Register (CPR)), two studies assessed parenting success through child outcomes (either child developmental outcomes or child problem behaviour) and one used a measure of quality of the home environment.

Finally, the studies utilised a variety of questionnaires and measures to measure potential risk factors: in addition to demographic characteristics, six studies used measures of social support, four examined mental or physical health, four looked at parental history of abuse, three specifically measured

parental IQ, two studies investigated stress and partner characteristics, while single studies looked at child characteristics and home environment.

The quality of these questionnaires varied substantially. While some measures had been designed specifically for parents with LD, and had been validated for use with that population, in other cases, measures validated for use with the general population were adapted by the authors for use with individuals with LD. One study used only non-standardised measures which were developed for the study in question (2), while others drew upon non-standardised questionnaires which had been used in previous research with parents with learning disabilities.

### *Key Findings*

The factors investigated in the eight studies can be broadly grouped into the following categories: social support; parental characteristics (including IQ, mental and physical health, history of trauma); and partner and child characteristics.

#### *Parental Characteristics (See Table 2)*

##### *IQ*

Perhaps the most controversial of the factors assumed to determine a person's ability to be a parent is their intellectual level. Three of the papers provided evidence for the impact of this factor. McGaw, Scully and Pritchard (2010) found no significant difference in the IQ of parents with LD whose children were placed on CPR compared to those whose were not, while

McConnell, Llewellyn, Mayes, Russo and Honey (2003) found no correlation between child developmental outcomes at two years of age and maternal IQ. Similarly, Keltner, Wise and Taylor (1999) found no correlation between maternal IQ and the rate of either psychomotor or mental development in their children. However, in this latter study, on further analysis, it emerged that, amongst a subgroup of parents with IQ<70 (rather than the original group with IQ < 75) there was a significant negative correlation between maternal IQ and child psychomotor (but not mental) development. The authors offer no suggestion as to what the proposed difference is for this specific subgroup of parents, or indeed, why they chose to distinguish between those with IQs of 70 and 75.

### *History of Trauma*

The impact of childhood sexual abuse on an individual's ability to parent has been well-documented (DiLillo & Damashek, 2003), with research suggesting that parenting is hindered through resulting mental health difficulties (Petterson & Albers, 2001) and the fact that victims of familial childhood sexual abuse may lack the opportunity to learn from healthy parenting models (Armsworth & Stronck, 1999). Equally, it has been shown that the prevalence of abuse is higher in children with LD (Balogh et al., 2001) and this may constitute an important factor in determining a person with LD's ability to parent. In the current review, four of the eight papers investigated the impact of childhood abuse on parental outcomes, with mixed results.

Table 2: Summary of studies investigating impact of personal characteristics on parental adequacy

Paper no.	Sample size	Parents IQ	Study aims	Study Type	Measure of parenting adequacy	Measure of factors influencing parental adequacy	Results relevant to review
7	32 mothers with LD	No Measure, All receiving support from LD services	To identify any relationship between social support, parenting style and home environment and to identify any relationship between parental stress, parenting style and child behaviour.	Cross-sectional	Child Behaviour Checklist	SF-36	No correlation between parental health and the problematic child behaviour
5	47 mothers with LD (30 with custody, 17 without)	No Measure, All receiving support from LD services	To compare the health, social networks and community involvement of those mothers with LD who still had custody of their children to those who did not.	Cross-sectional	Whether or not the mother retained custody of her child	SF-36	No difference between the two groups in terms of their mental or physical health
2	20 mothers with LD	60-85	To identify parenting perceptions and experiences of mothers with LD	Cross-sectional	Parental Attitude Q-Sort	Self-disclosed history of abuse	Mothers who did or did not report a history of abuse showed no difference in parental attitude

1	38 mothers with LD	Average: 60 Range: 38-75	To describe the risk of developmental delay in young children born to mothers with LD	Cross-sectional	Bayley Scales for Infant Development	Slosson Intelligence Test - Revised	Maternal IQ not correlated with mental or psychomotor development When only IQ's below 70 used, significant correlation between parental IQ and decreased psychomotor development in child
4	37 mothers with (or suspected of having) LD	Average: 72 Range: 40-97	To examine the relationship between child developmental status and various child, maternal and environmental characteristics	Cross-sectional	Developmental Profile II	Kaufman Brief Intelligence Test; SF-36	No correlation between developmental status and maternal health or maternal IQ
8	101 parents with LD (97 female, 4 male)	Average: 67 Range: 53-74	To establish whether familial and environmental factors differentiate high risk from low risk parents	Cross-sectional	Level of risk defined by whether child is on CPR	Parent Assessment Manual	No significant difference between high and low risk groups in terms of parental IQ; Increased risk associated with a history of childhood abuse and parental health

Ehlers-Flint (2002) found that whether or not a mother had been abused had no impact on any of four parental attitude scales (enjoyment of child, appropriate expectations, parental nurturance or appropriate discipline practices). Similarly, no relationship was found between maternal history of abuse and a child's developmental status at two years of age (McConnell, Llewellyn, Mayes, Russo & Honey, 2003). On the other hand, McGaw, Scully and Pritchard (2010) found that parents with children on CPR were significantly more likely to have experienced childhood trauma than parents whose children were not on CPR ( $\chi^2 = 6.18$ ,  $p = 0.01$ ), a result replicated by McGaw, Shaw and Beckley (2007). The former noted that this risk was particularly prominent for those who had experienced emotional abuse or physical neglect, while the latter found that emotional abuse had the biggest effect.

### *Physical and Mental Health*

Individuals with LD have a greater risk of experiencing co-morbid diagnoses than the general population (Goodinge, 2000) and it has been noted that amongst parents whose children are involved in child care proceedings, approximately 45% have an additional mental health diagnosis, outnumbering those with any physical or sensory difficulties (Booth, Booth & McConnell, 2005). Five of the current studies examined physical and mental health difficulties as a factor in determining parenting outcome. Three of these studies used the SF-36 as a measure of both physical and mental health in parents, and found no correlation between parental health and child

problem behaviours (Aunos, Feldman & Goupil, 2008) no difference in parental health between those who do or do not abuse their children (Aunos, Goupil & Feldman, 2004) and no relationship between maternal health status and child developmental outcomes (Llewellyn, Mayes, Russo & Honey, 2003). This is in contrast to the final two studies which reported associations between parental health and parenting ability. In the first, McGaw, Scully and Pritchard (2010) reported a trend towards significance, with those parents with additional mental, physical or sensory impairments being more likely to have a child on CPR ( $p = .08$ ). Focusing exclusively on mental health in parents, McGaw, Shaw and Beckley (2007) found evidence of significant associations between parental psychopathology and the presence of mental disorders in children, particularly between children with conduct disorder, anxiety and autism and parents with depression, anxiety and obsessive compulsive disorder. This discrepancy in findings across the studies might be explained by the use of different diagnostic classifications across studies, and in particular the use of a more generalised measure of health (e.g. SP-36) compared with the use of more specific measures of mental health (e.g. PAS-ADD).

#### *Partner and child characteristics (See Table 3)*

##### *Partner Characteristics*

Early studies into the significance of the partner of mothers with LD suggested that in general there was "*a strong tendency for like to marry like...but where exceptions occurred they tended to be associated with*



Table 3: Summary of studies investigating impact of partner and child characteristics on parental adequacy

Paper no.	Sample size	Parents IQ	Study aims	Study Type	Measure of parenting adequacy	Measure of factors influencing parental adequacy	Results relevant to review
5	47 mothers with LD (30 with custody, 17 without)	No Measure, All receiving support from LD services	To compare the health, social networks and community involvement of those mothers with LD who still had custody of their children to those who did not.	Cross-sectional	Whether or not the mother retained custody of her child	Questionnaire on family information; Child Behaviour Checklist	No difference between the two groups in terms of number of children or perception of child behaviour; Children were significantly younger in the group who still had custody
8	101 parents with LD (97 female, 4 male)	Average: 67 Range: 53-74	To establish whether familial and environmental factors differentiate high risk from low risk parents	Cross-sectional	Level of risk defined by whether child is on CPR	Parent Assessment Manual	Increased risk associated with higher partner IQ and a history of criminal or antisocial behaviour in the partner
6	49 parents (30 female, 19 male)	Average: 72 Range: 53-90	To investigate the incidence of childhood trauma and psychopathology across a population of parents with LD	Cross-sectional	Whether or not child is on CPR	Parent Assessment Manual	Children at greater risk of being placed on CPR when partner had IQ > 80

*unsatisfactory childcare*" (Mickelson, 1947). There has been little evidence to support this: as Munro (2005) notes, very little information tends to be gathered on the partners of women with LD in current practice. Only two of the current studies examined this issue. McGaw, Shaw and Beckley (2007) found that a significantly higher proportion of children were on CPR whose fathers had IQs over 80, than those whose fathers had IQs less than 80. Similarly, McGaw, Scully and Pritchard (2010) found that increasing partner IQ correlated significantly with risk to the child, in terms of their being placed on CPR. They claim that children of fathers with IQ between 70-84 were at three times greater risk than those with an IQ <70, while fathers with an IQ <85 were associated with a nine times greater risk. Additionally, the risk of abuse or neglect increased significantly when the partner had a history of criminal or antisocial behaviour. It should be noted that these results were based only on information available on approximately half of the partners of the mothers in the study.

#### *Child characteristics*

Although Belsky (1984) highlights the importance of child characteristics in a model of parenting, there has been little research to investigate whether this can be generalised to an LD population. Two of the current studies provide evidence to answer this question, although both as secondary aims. Firstly, Aunos, Goupil and Feldman (2004) found that while the number of children at home and the perceived behaviour of the child had no impact on the outcome of custody decisions, the children of those parents who retained

custody tended to be younger than those who were removed. This is in keeping with theories that as a child gets older, presenting new difficulties for the parent, and potentially surpassing the parent in ability, it becomes more difficult for an individual with LD to parent effectively. In addition, McGaw, Scully and Pritchard (2010) found that there was an increased risk associated with parents whose child had special needs ( $p = .04$ ).

*Social Support (See Table 4)*

The importance of having support available from family, friends, partners and professionals has been consistently highlighted in the literature around parents with LD (Tarleton & Ward, 2007). However, it has also been reported that mothers with LD are often single, tend to be socially isolated and struggle to form friendships in the community (e.g. Llewellyn & McConnell, 2000). Six of the current studies provided information on this topic, using a variety of measures to determine levels of social support. Again, results were mixed. In the two studies comparing high-risk with low-risk parents, McGaw, Scully and Pritchard (2010) found no difference between those parents whose children were on CPR compared to those whose children were not on CPR in terms of support and resources, while Aunos, Goupil and Feldman found there was no significant difference in size of social network between those who did or did not retain custody of their children. However, those who kept their children reported significantly more community involvement than those who did not ( $t = 2.25$ ;  $p < 0.05$ ).

Table 4: Summary of studies investigating impact of social support on parental adequacy

<b>Paper no.</b>	<b>Sample size</b>	<b>Parents IQ</b>	<b>Study aims</b>	<b>Study Type</b>	<b>Measure of parenting adequacy</b>	<b>Measure of factors influencing parental adequacy</b>	<b>Results relevant to review</b>
7	32 mothers with LD	No Measure, All receiving support from LD services	To identify any relationship between social support, parenting style and home environment and to identify any relationship between parental stress, parenting style and child behaviour.	Cross-sectional	Child Behaviour Checklist; Caldwell HOME Inventory; Canadian National Study on Children and Youth parenting questionnaire	Parenting Stress Index; Questionnaire on Social Support	No relationship between social support and either parenting style or home environment; Correlation between parenting stress and both child behaviour and parenting style
5	47 mothers with LD (30 with custody, 17 without)	No Measure, All receiving support from LD services	To compare the health, social networks and community involvement of mothers with LD who still had custody of their children to those without.	Cross-sectional	Whether or not the mother retained custody of her child	Community Involvement Scale; Questionnaire on social support;	No difference between the groups in social support; Those who kept custody showed greater community involvement and satisfaction with services

2	20 mothers with LD	60-85	To identify parenting perceptions and experiences of mothers with LD	Cross-sectional	Parental Attitude Q-Sort	Inventory of Social Contacts	No relationship between social support and parental attitudes
3	30 mothers with LD	No Measure, All receiving support from LD services	To investigate the relationship between stress, social support and mother-child interactions in an LD population	Cross-sectional	Observational Checklist for mother-child interactions	PSI; Telleen Parenting Social Support Index;	Correlation between satisfaction with social support and positive child interaction; No relationship between positive child interaction and any other measure of stress or social support
4	37 mothers with (or suspected of having) LD	Average: 72 Range: 40-97	To examine the relationship between child developmental status and various child, maternal and environmental characteristics	Cross-sectional	Developmental Profile II	HOME Inventory; Questionnaire on Family Structure	No correlation between developmental status and any measure of social support
8	101 parents with LD (97 female, 4 male)	Average: 67 Range: 53-74	To establish whether familial and environmental factors differentiate high risk from low risk parents	Cross-sectional	Level of risk defined by whether child is on CPR	Parent Assessment Manual	No significant difference between high and low risk groups in terms of social support, resources, relationship status or length of current relationship

Results also varied between those studies using direct measures of parenting: Ehlers-Flint (2002) found no relationship between parental attitude and social support, whether in terms of source of support (e.g. familial or therapeutic) or type of support (e.g. emotional or financial). Similarly, Aunos, Feldman and Goupil (2008) found no relationship between social support (either size or satisfaction) and parenting style. Feldman, Varghese, Ramsay and Rajska (2002), however, demonstrated that while there was no link between size of support network and quality of mother-child interactions, there was a correlation between increased Telleen satisfaction scores and positive mother-child interactions ( $r = 0.53$ ;  $p < 0.05$ ). In terms of child outcomes, McConnell, Llewellyn, Mayes, Russo and Honey (2003) established no relationship between child developmental status and nature of household structure.

Finally, two studies investigated the mediating role of stress. Aunos, Feldman & Goupil (2008) found a significant positive correlation between parental stress and child problem behaviours ( $r = 0.592$ ,  $p < 0.005$ ), and a significant negative correlation between parental stress and a positive parenting style ( $r = -0.416$ ,  $p < 0.005$ ). However, Feldman, Varghese, Ramsay and Rajska (2002) found no correlation between parental stress and mother-child interactions.

## **Discussion**

### *Support for Sterling's (1998) Model of parental adequacy in LD*

Sterling (1998) drew on Belsky's model of multiple determinants of parenting to propose a three-factor system impacting on parenting. In it, a parent's cognitive abilities, social support system and level of psychological

health are thought to determine the success of parenting, with social support mediating cognitive ability, and a bi-directional relationship between social support and psychological health. Evidence from this review partially supports Sterling's model.

In terms of cognitive abilities, evidence is particularly limited: two out of three papers found no evidence linking IQ to either child developmental status or risk, while the third only found a relationship between IQ and child development after altering their original definition of IQ. There is also no research available to support Sterling's claim that level of cognitive ability is mediated through contextual and social support factors.

Sterling's subsystem of psychological health places an emphasis on the presence or absence of depression in parents with LD. None of the studies focussed on depression in its own right, however of the five studies examining parental mental health, three studies found no link between parental mental health status and either child developmental outcome, child behaviour or outcome of custody proceedings. However, where a more in depth measure of mental health was used, significant associations were found between presence of psychopathology in the parent (e.g. anxiety and depression) and certain mental disorders in the child (e.g. conduct disorder). This suggests that parental psychological health may indeed be a factor in determining parental adequacy, but that the use of a specific assessment of mental health may be important. None of the studies provide evidence of causality, so Sterling's claim of a bi-directional relationship between social support and psychological well-being cannot be substantiated in the current review.

Sterling cites social support as the most important factor impacting on parental adequacy. While the studies in the current review support that to some extent, the evidence is not overwhelming. None of the studies found a relationship between size of social network and any outcomes of parental adequacy, however two of the studies found that satisfaction with the support received did influence parental adequacy. This seems to support Tucker and Johnson's (1989) finding that it is the kind of social support received that is crucial rather than the amount: they found that, in fact, certain types of social support actually inhibited parental competence rather than enhancing it.

Finally, Sterling ignores the role of child characteristics in her model of parenting adequacy, while combining the role of the partner within the subsystem of social support. The current evidence suggests that this was perhaps a hasty departure from Belsky's (1984) model. The influence of partner IQ was noted in two studies (where higher partner IQ was associated with increased risk to the child), while the impact of certain child characteristics such as age, child behaviour and special needs of the child were found to play a role.

### *Methodological Issues*

One clear methodological difficulty within the studies as a group is their lack of definitive definition of what constitutes a learning disability in terms of IQ. While most authors cited the standard definition of an IQ  $< 70 \pm 5$ , only two studies used this as an upper limit for participant inclusion. Three studies provided no information on the IQ of participants, while three studies included parents with IQs up to 85, 90 and 97. At the lower end,



two studies reported IQ ranges starting from 36 and 40. It seems clear that the expected difficulties in parenting faced by individuals with IQs of 36 and 97, would be so different as to be virtually incomparable. Such a wide ranging set of IQs does not represent a homogeneous group representative of individuals with LD.

Similarly, comparison even within an individual factor such as social support proved difficult, given that each of the six studies investigating the factor used different measures to assess levels of social support. None of the measures used had established norms for individuals with LD and different measures placed different emphasis on, for instance, make-up of the social network versus satisfaction with social support.

Nearly all of the measure used across the studies relied on self-report from the participating parents. One exception to this was the use of the CBCL, where both the parent and a professional involved in the parents care were asked to rate the child's behaviour to ensure reliability between the professional's and the parent's perception. While the problems associated with self-report questionnaires in research has been well-documented, the use of self-report questionnaires with people with LD is particularly problematic (Finlay & Lyons, 2001), with issues such as acquiescence and reliability of historical information provided. Assessing a history of abuse, equally, within a research context is likely to result in an underestimation of prevalence of abuse.

Where measures of child development or behaviour were used, it was interesting to note that if multiple children resided at home, only one child was included. The method of choosing which child to select varied amongst

studies. Two studies used the oldest child, one used the youngest child and one selected a random child. Although it is not clear what, if any, impact this might have, the age of a child has been found to have a significant impact on a parents' ability to cope (Aunos, Goupil & Feldman, 2004).

In general, the articles included in this study recruited small number of participants, with the exception of those studies using a retrospective design. In addition, the articles in this review lean massively towards the inclusion of mothers with LD rather than fathers with LD, reflecting the status of research into parents with a learning LD as a whole. Given this bias, it is difficult to generalise the results of this review to fathers with LD. Finally, the samples used in all of these studies are either recruited from a group of parents in receipt of learning disability services or reflect the histories and circumstances of those parents involved in care proceedings for their children. It is likely, therefore, that participants reflect a group of parents with more complex needs than those parents with LD who are not in receipt of any services.

### *Study limitations*

The primary limitation to the current study was in attempting to compare differing outcome variables as a measure of parental adequacy. While all three outcome areas are used in the literature, there are questions around how valid these are in determining parental adequacy. For child developmental outcomes, in particular, there are clear confounding variables such as genetic heritability, which need to be accounted for, although attempts were made to control for this in at least one study. Similarly, using the outcomes of care proceedings as a measure of parental

adequacy is open to the same bias which the parents themselves face: the fact that a child is removed does not necessarily equate to parental inadequacy. Nevertheless, until the research base expands and a more relevant way of assessing parental adequacy in people with LD is developed, all three methods provide a useful starting point for investigation. In addition, given the relatively small number of studies included within the review, there can only be limited strength in the conclusions drawn.

### *Future research*

There are several clear directions for future research, not least of which is the inclusion of fathers with LD within research. It seems implausible that the proportion of fathers with learning disabilities is so low, and it may be a vital first step to investigate why these fathers are not accessing support. Furthermore, in order for findings to be generalisable, it will be important to recruit and include those parents not in receipt of any services. Given the inconsistencies in the results discussed in the current review, it is recommended that these studies be replicated with attention paid to increased sample size, definition of key factors, use of validated measures and stricter inclusion criteria with regard to level of LD. In the future, it will also be important to investigate the mechanisms by which these factors influence parental adequacy, and to use more appropriate methodological designs to allow discussion of causality. Finally, it may be important within factors such as cognitive ability, not to focus solely on IQ, but to investigate the impact of deficiencies in specific areas such as problem-solving or decision-making.

### *Implications for practice*

Professionals are often tasked with determining level of risk for parents with learning disabilities. It is hoped that through an increased understanding of risk factors associated with parental adequacy, this assessment might be more accurate and less open to bias. The review clearly indicates that merely having LD does not preclude one from being a successful parent, and this may go some way to dispelling the stereotypes faced by parents with LD. In practical terms, these findings suggest that a greater importance should be placed on taking a thorough social history of parents and that there should be an emphasis on seeking information about any involved partners. The evolving difficulties faced by parents as a child gets older highlights the need for services to be adaptable and flexible in their support of parents throughout the child's lifespan. Finally, given that it has been found that satisfaction with social support is crucial, services should ensure that they seek feedback from parents as to whether the support provided is meeting their perceived needs.

### *Conclusions*

Despite this being a replication of a review conducted close to twenty years ago, this remains only a useful starting point in determining what factors influence parental adequacy in people with LD. Many of the methodological flaws and biases highlighted in the previous review have not been addressed in subsequent research, and much of the resulting evidence is contradictory. Nevertheless, there is evidence to suggest that quality rather than pure availability of social support is crucial, and that parental, partner and child characteristics should be considered in any model of parental

adequacy in parents with learning disabilities. Given the importance placed on assessment of parenting skills in court proceedings, it is crucial that these factors be better understood by clinicians.

### References

- Abidin, R. R. (1990). *Parenting Stress Index – Manual*. Charlottesville, VA: Pediatric Psychology Press.
- Accardo, P. J. & Whitman, B. Y. (1989). Factors influencing child abuse/neglect in children of mentally retarded parents. *Pediatric Research*, 25, 95.
- Accardo, P. J. & Whitman, B. Y. (1990). Children of mentally retarded parents. *American Journal of Disease in Children*, 144, 69-70.
- Achenbach, T. M. (1988). *Child Behaviour Checklist*. Burlington: University of Vermont.
- Alpern, G. A., Boll, T. & Shearer, M. A. (1995). *Developmental Profile II manual*. California: Western Psychological Services.
- Armstrong, R. & Jensen, R. A. (1984). *Slosson Intelligence Test*. New York: Metrics.
- Armsworth, M. W., & Stronck, K. (1999). Intergenerational effects of abuse on parenting: Skills, abilities, and attitudes. *Journal of Counseling and Development*, 77, 303-314.
- Aunos, M., Goupil, G., & Feldman, M.A. (2003). Mothers with intellectual disabilities who do and do not have custody of their children. *Journal of Developmental Disabilities*, 10, 65-79.
- Aunos, M., Feldman, M.A, & Goupil, G. (2008). Mothering with intellectual disabilities: Relationship between social support, health and well-being, parenting and child behaviours outcomes. *Journal of Applied Research in Intellectual Disabilities*, 21, 320-330.

- Balogh, R., Bretherton, K., Whibley, S., Berney, T., Graham, S., Richold, P., Worsley, C. & Firth, H. (2001). Sexual Abuse in children and adolescents with intellectual disability. *Journal of Intellectual Disability Research*, 45, 194-201.
- Bayley, N. (1984). *Manual for the Bayley Scales of Infant Development*, 2<sup>nd</sup> ed., *Manual*. San Antonio, TX: Harcourt, Brace & Company.
- Belsky, J. (1984). The determinants of parenting: a process model. *Child Development*, 55, 83-96.
- Belsky, J., Woodworth, S., Crnic, K. (1996). Trouble in the second year: Three questions about family interaction. *Child Development*, 67, 556-578.
- Bernstein, D. P. & Fink, L. (1998). *Childhood Trauma Questionnaire*. San Antonio, TX: The Psychological Corporation.
- Block, J. H. (1965). *The Child-Rearing Practices Report: A set of Q items for the description of parental socialization attitudes and values*. Berkley: Institute of Human Development.
- Booth, T. (2000). Parents with learning difficulties, child protection and the courts. *Representing Children*, 13, 175-188.
- Booth, T. & Booth, W. (1994). *Parenting Under Pressure: Mothers and Fathers with Learning Difficulties*. Open University Press, UK.
- Booth, T. & Booth, W. (2000). Against the odds: Growing up with parents who have learning difficulties. *Mental Retardation*, 38, 1-14.
- Booth, T., Booth, W. & McConnell, D. (2005). The prevalence and outcomes of care proceedings involving parents with learning difficulties in the Family Courts. *Journal of Applied Research in Intellectual Disabilities*, 18, 7-17.
- Borgman, R. D. (1969). Intelligence and maternal inadequacy. *Child Welfare*, 48, 301-304.

- Bradley, R., Toft, S. & Collins, G. (2000). Parenting Assessments. *Learning Disability Practice*, 2, (5), 9–11.
- Caldwell, B. M. & Bradley, R. H. (1984). *Home observation for measurement of the environment*. Little Rock: University of Arkansas.
- Cohen, S. & Hoberman, H. M. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology*, 13, 99-125.
- Cooper, S., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190, 27-35.
- Crawford, J. R., Gray, C. D., & Allan, K. M. (1995). The WAIS – R (UK): Basic psychometric properties in an adult UK sample. *British Journal of Clinical Psychology*, 34, 237–250.
- Department of Health (2000). *Framework for the assessment of children in need*. London: The Stationary Office.
- Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: The Stationary Office.
- Department of Health (2007). *Good Practice Guidance on Working with Parents with a Learning Disability*. London: The Stationary Office.
- DiLillo, D., & Damashek, A. (2003). Parenting characteristics of women reporting a history of childhood sexual abuse. *Child Maltreatment*, 8, 319-333.
- Dowdney, L. and Skuse, D. (1993). Parenting provided by adults with mental retardation. *Journal of Child Psychology and Child Psychiatry*, 34, 25-47.
- Ehlers-Flint, M. L. (2002). Parenting Perceptions and Social Supports of Mothers with Cognitive Disabilities. *Sexuality and Disability*, 20, 29-51.

- Feldman, M. A., Leger, M. & Walton-Allen, N. (1997). Stress in mothers with intellectual disabilities. *Journal of Child and Family Studies*, 6, 471–485.
- Feldman, M.A., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationships between social support, stress, mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 314-323.
- Finlay, W. M. & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, 13, 319-335.
- Gillberg, C. & Geijer-Karlsson, M. (1983). Children born to mentally retarded women: A 1–21 year follow-up study of 41 cases. *Psychological Medicine*, 13, 891–894.
- Goodinge, S. (2000). *A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role*. London: DH
- Guinea, S. (2001). Parents with a Learning Disability and their Views on Support Received: A Preliminary Study. *Journal of Intellectual Disabilities*, 5, 43 – 56.
- Hayman, R.L. (1990). Presumptions of justice: Law, politics, and the mentally retarded parent. *Harvard Law Review*, 103, 1201–1271.
- Herzog, R., Álvarez-Pasquin, M. J., Díaz, C., Del Barrio, J. L., Estrada, J. M., & Gil, Á. (2013). Are healthcare workers' intentions to vaccinate related to their knowledge, beliefs and attitudes? A systematic review. *BMC Public Health*, 13(1), 1-17.
- Kaufman, A. S., & Kaufman, N. L. (1990). *Kaufman Brief Intelligence Test*. Circle Pines: American Guidance Services.
- Keltner, B., Wise, L., & Taylor, G. (1999). Mothers with intellectual limitations and their 2-year-old children's developmental outcomes. *Journal of Intellectual and Developmental Disability*, 24, 45–57.



- Levesque, R. J. R. (1996). Maintaining children's relations with mentally disabled parents: Recognizing difference and the difference that it makes. *Children's Legal Rights Journal*, 16, 14–22.
- Llewellyn, G. (1995). Relationship and social support: views of parents with mental retardation/ intellectual disability. *Mental Retardation*, 33, 349–363.
- Mansell, J., & West, M. (2000). *Supporting parents with learning disabilities in Rotherham*. Rotherham: Rotherham Advocacy Partnerships.
- McConnell, D. & Llewellyn, G. (2000). Disability and discrimination in statutory child protection proceedings. *Disability and Society*, 15, 883–895.
- McConnell, D., Llewellyn, G., Mayes, R., Russo, D., & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual & Developmental Disability*, 28, 122–134.
- McConnell, D., Mayes, R., & Llewellyn, G. (2008). Pre partum distress in women with intellectual disabilities. *Journal of Intellectual and Developmental Disability*, 33, 117–183.
- McGaw, S., Beckley, K., Connolly, N. & Ball, K. (1998). *Parent Assessment Manual*. Truro, NS: Special Parenting Service, Cornwall Partnership (NHS) Trust.
- McGaw, S. Shaw, T, Scully, T. & Pritchard, C. (2010). Predicting the Unpredictable? Identifying high risk versus low risk parents with intellectual disabilities. *Child Abuse & Neglect*, 34, 699–710.
- McGaw, S., Shaw, T., & Beckley, K. (2007). Prevalence of psychopathology Parents' with LD psychological wellbeing and social support across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 11–22.

- Mickelson, P. (1947). The feeble-minded parent: A study of 90 family cases. *American Journal of Mental Deficiency, 51*, 644–653.
- Mirfin-Veitch, B., Bray, A., Williams, S., Clarkson, J. & Belton, A. (1999). Supporting parents with intellectual disabilities. *New Zealand Journal of Disability Studies, 6*, 60–74.
- Munro, E. (2005). What tools do we need to improve identification of child abuse? *Child Abuse Review, 14*, 374–388.
- Myers, F., Ager, A., Kerr, P. & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability and Society, 13*, 389–413.
- Naglieri, J. A., Le Buffe, P. & Pfeiffer, S. I. (1994). *Devereux scales of mental disorders*. San Antonio, TX: The Psychological Corporation.
- Nicholson, J. (1997) *Parents with Learning Disabilities: A Survey of Current Services in the Mansfield and Ashfield areas*. Central Nottinghamshire Healthcare Trust, Mansfield.
- Prosser, H., Moss, S., Costello, H., Simpson, N. & Patel, P. (1997). *The Mini PAS-ADD – An assessment schedule for the detection of mental health problems in adults with developmental disabilities*. Manchester: University of Manchester.
- Rodgers, A. Y. (2000). Multiple sources of stress and parenting behavior. *Children and Youth Services Review, 20*, 525–546.
- Rothenbuhler, E. (1991). The process of community involvement. *Communication Monographs, 58*, 63–78.
- Schilling, R. F., Schinke, S. P., Blythe, B. J. & Barth, R. P. (1982). Child maltreatment and mentally retarded parents: Is there a relationship? *Mental Retardation, 20*, 201–209.
- Shaw, C. H. and Wright, C. H. (1960). The married mental defective. A follow up study. *The Lancet, 30*, 273–274.

- Sterling, J.D. (1999). *Determinants of parenting in women with mental retardation*. Ann Arbor, MI: The Fielding Institute.
- Tarleton, B. & Ward, L. (2007). "Parenting with support": The views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 194-202.
- Tarleton, B., Ward, L. & Howarth, J. (2006). *Finding the right support?* London: Baring Foundation.
- Telleen, S. (1985). *Parenting Social Support Index: Reliability and Validity*. Chicago, IL: University of Illinois.
- Tucker B. M. & Johnson O. (1989) Competence promoting versus competence inhibiting social support for mentally retarded mothers. *Human Organization*, 48, 95–107.
- Tymchuk, A. J. & Andron, L. (1990). Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect*, 14, 313–323.
- Tymchuk, A. J., Andron, L. & Unger, O. (1987). Parents with mental handicaps and adequate child care: a review. *Mental Handicap*, 15, 49–54.
- Ware, J. E., Snow, K., Kosinski, M. & Gandek, B. (1993). *SF-36 health survey manual and interpretation guide*. Massachusetts: The Health Institute, New England Medical Centre.
- Wechsler, D. (1998). *Wechsler adult intelligence scale – III, UK*. London: The Psychological Corporation.
- Wells, G. A., Shea, B., O'connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2000). The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses.
- Wilms, J. D. (2002). *Vulnerable Children*. Edmonton: University of Alberta.
- Young, S. & Hawkins, T. (2005). Special parenting and the combined skills model. *Journal of Applied Research in Intellectual Disabilities*, 19, 346-355.

## **Journal Paper**

The following article is prepared for submission to:

**Journal of Applied Research in Intellectual Disabilities**

**PARENTS WITH LEARNING DISABILITIES:  
PERCEPTION OF ASSUMPTIONS MADE BY HEALTH  
AND SOCIAL CARE PROFESSIONALS ABOUT THEIR  
RIGHT AND ABILITY TO BE A PARENT**

**Running Title:**

'Assumptions about parents with learning disabilities'

Joanna Rose<sup>1</sup>, Rachel Sabin-Farrell<sup>2</sup>, & Anne-Marie Mensink<sup>3</sup>

<sup>1</sup> Trent Doctorate in Clinical Psychology, University of Lincoln, Lincolnshire, UK.

<sup>2</sup> Trent Doctorate in Clinical Psychology, University of Nottingham, Nottinghamshire, UK.

<sup>3</sup> Norfolk Community Health and Care NHS Trust, Norfolk, UK.

**Corresponding Author:**

Joanna Rose, University of Lincoln, Health Life and Social Sciences, 1<sup>st</sup> Floor, Bridge House, Brayford Pool, Lincoln, LN6 7TS

10197388@students.lincoln.ac.uk

**Keywords:**

learning disabilities; intellectual disabilities; parents; assumptions; professionals

## **Abstract**

*Background:* Parents with learning disabilities (LD) face potential discrimination based on negative assumptions about their ability and right to be parents.

*Method:* Thematic analysis was used to explore the experiences and perceptions of ten parents with LD with regard to the assumptions made by health and social care professionals.

*Results:* Four themes were identified relating to: the specific assumptions parents attributed to professionals; the treatment they have experienced which was related to their predictions of assumptions; the impact of such assumptions on parents, both in terms of emotional consequences and willingness to engage; and the extent to which parents internalised such assumptions.

*Conclusion:* Participants were aware of negative assumptions surrounding their status as parents, and attributed these to professionals they are working with. Given the impact on parents, results suggest that consideration needs to be paid to the nature of support provided and addressing lingering unfounded stereotypes about parents with LD.

## Introduction

The challenges facing parents with LD<sup>2</sup> are attracting increasing interest in the form of research and UK government policy. People with LD have traditionally been excluded from aspects of society, particularly in terms of sexuality and parenthood. In fact, driven by the eugenics movement<sup>3</sup> of the 1930s, England's 'mentally deficient' were dangerously close to becoming subject to involuntary sterilisation programmes (Thomson, 1998). Thanks, partially, to British ideals of civil liberties, this legislation was never passed. However, the assumption that 'breeding' between 'mental deficients' would lead to the degeneration of the species, remained influential for several decades.

Establishing the prevalence of parents with LD has proved difficult, in part due to inconsistency of definition<sup>4</sup>. UK estimates place numbers anywhere between 23,000 and 250,000 (Department of Health (DoH), 2007)<sup>5</sup>. Despite this lack of consensus, it is agreed that the number of parents with LD is rapidly increasing, as ideas of normalisation and inclusion<sup>6</sup> present people with LD with opportunities to become more integrated in communities (Pixa-Kettner, 2008). Audits of UK psychology departments in Nottingham (Bradley et al., 2000) and Swansea (Woodhouse et al., 2001) have reported sharp increases in referrals.

---

<sup>2</sup> See section 1.1.2 for discussion of terminology of 'learning disability'.

<sup>3</sup> See section 1.2.1 for a historical perspective on attitudes towards people with LD, from the eugenics movements through to the present day.

<sup>4</sup> Section 1.1.1 discusses the definition of learning disabilities.

<sup>5</sup> Section 1.1.3 provides further information on the prevalence of parents with LD worldwide.

<sup>6</sup> Further details of the inclusion movement are provided in Section 1.2.2.

Although the number of parents with LD is increasing, they face a battle to maintain custody of their children<sup>7</sup>. It has been consistently shown that 40-50% of children born to parents with LD are removed (Tarleton et al., 2006). Similarly, these parents are significantly over-represented in child protection proceedings, forming up to 15% of court samples (Booth & Booth, 2004). Where parents with LD were compared to a control group of parents without LD, the labelled group were more likely to have had their children removed even when guilty of the same neglect (Cleaver & Nicholson, 2003). When examining court reports in more detail, an LD diagnosis was often cited as a causative factor in decision-making (Booth et al., 2005).

Given the potential discrimination faced by parents with LD, it is likely that their treatment is based on a number of assumptions. Espe-Scherwindt and Crable (1993) identified four prominent myths surrounding parents with LD:

- Their children will have developmental difficulties
- They will be inadequate parents
- They will have large numbers of children
- They will be unable to learn parenting skills.<sup>8</sup>

Although early research supported and propagated such myths, influenced by the lingering eugenic agenda, extensive recent research has provided little empirical evidence to support such assumptions (Wade et al., 2008)<sup>9</sup>.

---

<sup>7</sup> Section 1.3.1 describes evidence of discrimination against people with LD in court proceedings.

<sup>8</sup> Section 1.2.3 provides up-to-date information regarding myths.

<sup>9</sup> See section 1.2.4 for extended evidence refuting the validity of the myths surrounding parents with LD.



In fact, it is increasingly shown that IQ has no systematic link to parenting success until IQ falls below 55 (Tymchuck & Andron, 1990), with multiple factors contributing to successful parenting<sup>10</sup>. McGaha (2002) suggests an epigenetic explanation of parental adequacy for parents with LD, in which a parent's developmental history alongside environmental factors interact to influence parenting outcomes. This was expanded by Feldman (2002), who highlights the impact of stigmatization and discrimination on parenting in people with LD, both through their effect on parents' mental health and through their effect on service provision.

Given the potential impact of stigmatization and discrimination, it is important to consider the attitudes that professionals<sup>11</sup> may hold. Historically, professionals have held disapproving and conservative attitudes towards sexuality and parenting in people with LD (Aunos & Feldman, 2002). Although attitudes appear to be moving towards ideals of normalisation, a significant proportion of professionals remain uneasy about people with mild LD engaging in sexual relationships, let alone becoming parents (Evans et al., 2009)<sup>12</sup>.

Stereotypical attitudes have the potential to affect parents with LD in two main ways: through the direct impact of stigma on mental health and self-beliefs; and through altered professional treatment. As with many populations, perception of stigma is related to reduced self-esteem (Abraham, et al., 2002) and mood (Dagnan & Waring, 2004) in people with LD. It is suggested that some people with LD remain unaware of stigma,

---

<sup>10</sup> See sections 1.4.1 for a discussion of factors influencing parental adequacy in parents with LD.

<sup>11</sup> In the current study, 'professional' is taken to mean any health or social care professional working with people with LD.

<sup>12</sup> Section 1.2.5 provides a full review of professional attitudes towards sexuality and parenthood in people with LD.

due to difficulties seeing things from another's perspective (Todd, 2000). However, the more aware a person with LD is of other people's assumptions, the lower their self-esteem (Paterson et al., 2012). Additionally, parents with LD might 'self-stigmatize'. In other words, they would be aware of stigma, agree with it and apply it to themselves (Corrigan et al., 2009)<sup>13</sup>.

Parents with LD are rarely asked to share their perspectives in research<sup>14</sup>. Where their opinion has been sought, findings are consistent: they are treated differently by services and do not feel listened to (Tarleton & Ward, 2007; Booth & Booth, 2004). Ajzen's (1985) theory of planned behaviour offers a perspective on this situation. The ability of attitudes and stereotypes to predict behaviour is not straightforward. However, implicit and explicit attitudes towards a stigmatised group can indicate a broader pattern of discriminative behaviour, when such behaviour conforms to social norms (Ajzen & Fishbein, 2004)<sup>15</sup>. It is therefore possible that some professionals working with parents with LD might act in a way, either consciously or unconsciously, that is consistent with stereotypical attitudes<sup>16</sup>.

Recent UK government policy has sought to address the specific challenges parents with LD might face, and the support they should expect to receive. However, even with the publication of documents such as 'Valuing People' (DoH, 2001) and 'Good Practice Guidance for working with Parents with Learning Disabilities' (DoH, 2007), the reality of service provision varies

---

<sup>13</sup> See section 1.3.2 for extended consideration of stigma in LD populations.

<sup>14</sup> See section 1.5 for more detail regarding parents' views of services.

<sup>15</sup> Section 1.3.3 offers a fuller explanation of the Theory of Planned Behaviour.

<sup>16</sup> Section 1.3.4 considers the ways attitudes might influence behaviour in professionals supporting parents with LD.

across the UK<sup>17</sup>, often falling short of expectations (Goodinge, 2000), and assessments by professionals remain open to bias (McGaw et al., 2010)<sup>18</sup>.

No study to date has examined the treatment parents with LD receive from professionals and the assumptions this treatment is perceived to be based on, from the perspective of parents themselves. This is of particular importance given the mounting claims of discrimination in the child protection system (Booth et al., 2005) and the recognition that government policy has had limited impact in improving their experiences of services (DoH, 2009). This study will therefore address four main research questions, with the aim of investigating the impact of assumptions about parents with LD on their parenting experience:

1. What expectations do parents with LD have about the assumptions professionals make about them as parents?
2. How do parents perceive the treatment they experience by professionals in their parenting role?
3. What impact do these expectations have on parents with LD?
4. What assumptions do parents with LD make about themselves as parents?

## **Method**

### *Design*

A qualitative research design was used, employing thematic analysis to analyse transcripts of interviews with parents with LD. Thematic analysis is a method of identifying, organising and interpreting patterns within

---

<sup>17</sup> See Section 1.4.3 for consideration of regional variability in service provision.

<sup>18</sup> See section 1.4.2 for further information regarding assessment of parenting abilities in parents with LD.

linguistic data (Braun & Clarke, 2006), and was chosen to provide a detailed but structured account of the way people with LD experience parenthood<sup>19</sup>. A semi-structured interview schedule, employing open-ended questions, was utilised to examine parents' perspectives of working with professionals.

### *Inclusion Criteria*

Parents were eligible to participate if they met the following criteria: they had at least one child living at home; they received support from specialist LD services; and their parenting skills had been assessed<sup>20</sup>. Additionally, potential participants required sufficient verbal ability to engage in interviews and needed capacity to consent to take part.

### *Sampling*

Participants were recruited using purposive sampling through Community Learning Disability Teams (CLDTs) across Norfolk, Lincolnshire and Nottinghamshire. Multi-disciplinary staff were sent information<sup>21</sup> and asked to identify suitable service users. Participants were identified through psychologists (n=8), psychiatrists (n=2), nurses (n=2) and social workers (n=2). Fourteen eligible parents were approached, of whom ten agreed to participate. Reasons for non-participation included insufficient time and unsettled mental health.

### *Participants*

In total, six mothers and four fathers were interviewed. This included three sets of couples, within which each parent was interviewed independently.

---

<sup>19</sup> See section 2.1 for a more detailed discussion of thematic analysis.

<sup>20</sup> See section 2.2 for justification of inclusion criteria.

<sup>21</sup> See Appendix C for professional information sheet.

Six participants were recruited from Norfolk, two from Lincolnshire and two from Nottinghamshire. The sample comprised families with a range of characteristics related to family structure and level of support received. See Table 5 for demographic information<sup>22</sup>. None of the participants were currently employed and, with the exception of Alan, had all attended a special school. All participants were identified as having a 'mild' LD.

Table 5: Demographic Information of participants

<u>Name</u>	<u>Age</u>	<u>Marital status</u>	<u>Children at home</u>	<u>Age of child</u>	<u>Other Children</u>	<u>Parental Health issues</u>	<u>Child Health issues</u>
Joyce	41	Husband w/o LD	1	16	1 removed	Epilepsy	None
Laura	30	Married to Larry	1	2	N/A	Epilepsy, Anxiety	None
Larry	35	Married to Laura	1	2	N/A	Anxiety	None
Alan	45	Married to Esther	1	6	N/A	None	Severe LD
Esther	45	Married to Andrew	1	6	N/A	Cerebral Palsy	Severe LD
Fiona	36	Partner w/o LD	2	12 & 16	N/A	Depression	1 Child with LD
Greg	38	Single	1	15	N/A	None	Emotional difficulties
Tommy	51	Married to Deborah	1	13	1 removed	Deaf	Moderate LD
Danielle	45	Married to Tommy	1	13	1 removed	None	Moderate LD
Georgia	33	Partner w/o LD	3	2, 5 & 9	N/A	None	None

## *Measures*

Participants provided demographic information verbally during the interview and gave permission for access to previously administered cognitive

<sup>22</sup> Section 2.3 provides fuller participant synopses (Pseudonyms used throughout).

assessments. Nine participants had accessible results from the Wechsler Adult Intelligence Scale (WAIS-III, 1997).

The interview schedule was developed by the researchers with the cognitive ability of participants in mind<sup>23</sup>. The schedule included open-ended questions, with prompts included to facilitate understanding if necessary<sup>24</sup>. The schedule covered eight topic areas, including: decisions and expectations of parenthood; experience of parenting assessments; expectation and experience of professionals' attitudes. The schedule was designed for flexible use depending on the ability of the participant. Care was taken in the phrasing of questions to ensure they were comprehensible for participants (Booth & Booth, 1996).

### *Procedure*

Ethical approval was received from the Leicester Research Ethics Committee, the University of Lincoln and relevant NHS Research and Development departments<sup>25</sup>. Participants were informed of the research by CLDT staff and provided with an information sheet<sup>26</sup>. If permission was given, contact details were passed to the principal researcher. Participants were contacted to arrange a meeting with the principal researcher and a familiar CLDT member, to ensure participants' capacity to consent. At this meeting, participants provided written informed consent<sup>27</sup> and a time and place was arranged to conduct the interview. All participants preferred to be interviewed at home, with interviews lasting an average of 60 minutes,

---

<sup>23</sup> See Appendix D for Interview Schedule.

<sup>24</sup> See section 2.4 for an overview of the use of qualitative methods with people with LD.

<sup>25</sup> See section 2.5 for a consideration of ethical issues. See Appendix E for letters of approval from all relevant committees.

<sup>26</sup> See Appendix F for Participant Information Sheet.

<sup>27</sup> See Appendix G for Participant Consent Form.

ranging from 45-90 minutes. Interviews were digitally recorded, transcribed verbatim by the principal researcher and anonymised to ensure participants' confidentiality.

### *Analysis*

Transcripts were analysed using manifest-level thematic analysis, as described by Braun and Clarke (2006). The research was grounded in a critical realist framework, with a constructionist slant (Willig, 1999). This position assumes that a 'reality' does exist, even though we cannot fully apprehend it, but that through intense critical examination, one may gain a useful understanding of it (Guba & Lincoln, 1994). In thematic analysis, this position supposes that one can gain insight into a person's experiences through their accounts, while acknowledging an element of construction of knowledge by the researchers (Madill et al., 2000)<sup>28</sup>. It is important therefore, to acknowledge the position of the researcher: as a professional who has worked within LD services for many years, the principal researcher adopts a role as an advocate for people with LD, while simultaneously recognising the potential difficulties they may face in their role as parents.

Initial codes were developed after the transcription of each interview by the first author, using a combination of inductive and deductive processes, with analysis driven both by the data and pre-existing theoretical concepts. After extensive familiarisation with the data set, which began with transcription and involved repeated reading of data, initial codes were developed and noted manually next to relevant data segments<sup>29</sup>. All

---

<sup>28</sup> See section 2.6 for a discussion of the researcher's epistemological position.

<sup>29</sup> See Appendix H for an extract of an interview with initial and final codes.

occurrences of the same code were physically collated together<sup>30</sup>. Subsequently, codes were sorted into potential super-ordinate and sub-themes, which were continually reviewed, revised and checked for internal homogeneity and external heterogeneity to ensure that data within each theme was coherent, yet with clear distinctions between themes. Themes were then organised into a final thematic map and defined according to their content. Reliability of codes was established by the reviewing of two transcripts by the second author<sup>31</sup>. Codes generated by the two authors were compared, with inconsistencies discussed and reconciled (Fereday & Muir-Cochrane, 2006). Finally, a third researcher checked the coherence of the overarching themes prior to the development of the final thematic map.

## **Results**

The following results are presented with reference to a thematic map (see Figure 3), which provides an overview of the main themes and subthemes, and their inter-relations. Four super-ordinate themes were identified, each with several subthemes<sup>32</sup>.

### *Parents' expectation of assumptions made by professionals*

The first over-arching theme considers the kinds of assumptions<sup>33</sup> parents attribute to professionals. Few parents had experienced directly expressed assumptions, meaning that in the majority of instances, professionals' assumptions were inferred. Where assumptions were directly expressed, it

---

<sup>30</sup> See Appendix I for an example of collated extracts for two individual codes.

<sup>31</sup> See section 2.7 for a discussion of reliability and validity in qualitative research.

<sup>32</sup> See section 3.1 for an overview of extended results.

<sup>33</sup> Although assumptions have the potential to be positive or negative, no parents attributed positive assumptions to professionals.



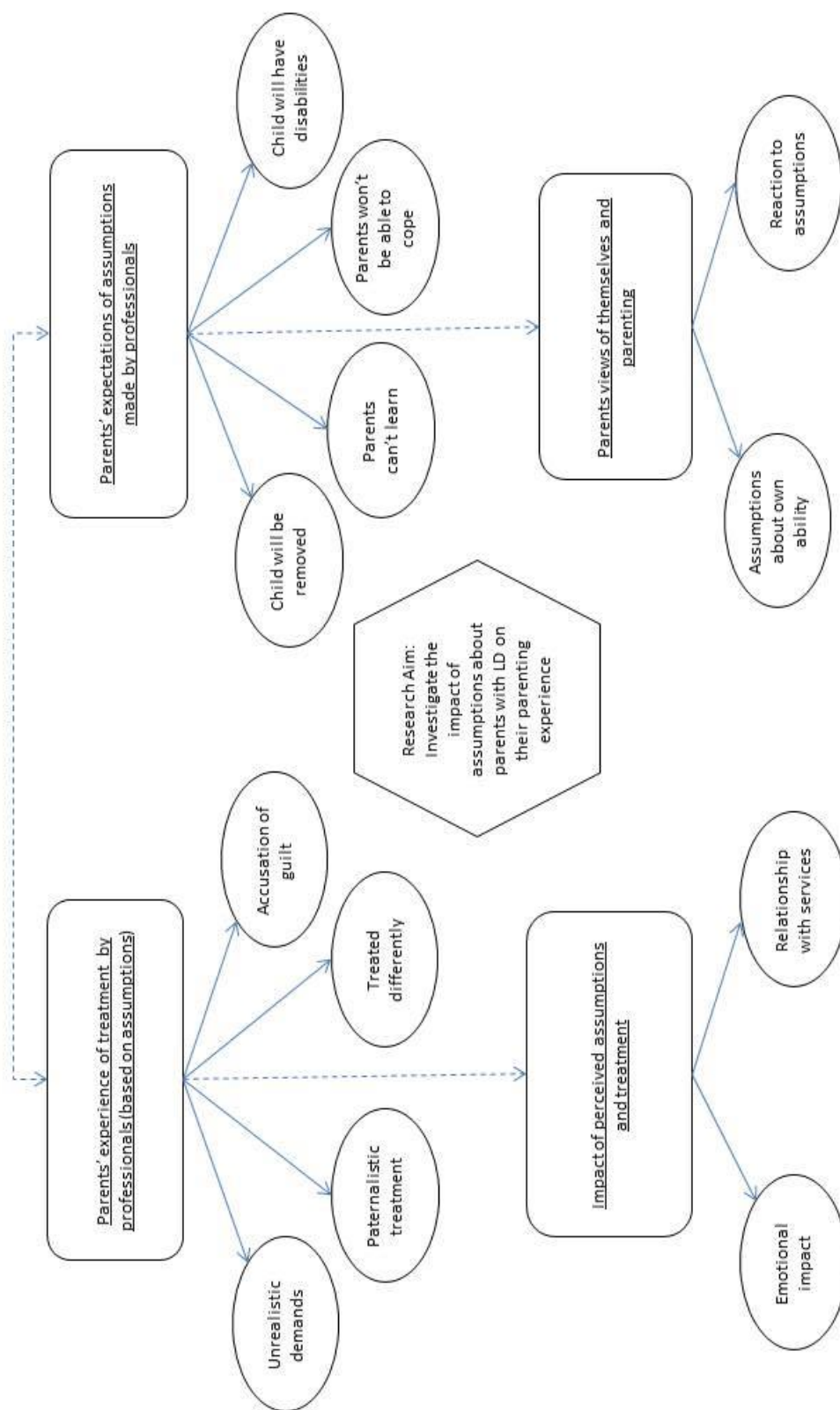


Figure 3: Thematic map

was often by a single person. For instance, Joyce was advised by her doctor that she shouldn't have children due to her LD:

Joyce: My doctor didn't want me to try for a baby though, but that weren't gonna stop me trying, so she said that I wouldn't be able to look after one.

Two of the parents, Greg and Danielle, claimed to have received letters from social services stating their ability to cope was being questioned due to their LD:

Danielle: And I didn't like it when I got a letter, said I can't have Leanne, said to me, 'Oh, we have to take Leanne because you got a learning difficulties'... They took Leanne in foster care because I've got a learning difficulties... it were there in the letter, and I got hold of it and teared it, and it actually said. I weren't very happy about that, I teared it. Should've saved that, they could get done for that.

For a minority of parents, their physical health problems were of additional concern for professionals. In these cases, it is unclear whether assumptions were made about the parents' LD, or other difficulties. Alan commented on this situation in relation to his wife:

Alan: Well, we'd been told that your child is more likely to come out with lots of problems, if it survives... Because of Esther's problems. So we was advised not to actually, obviously she ignored it anyway. She's got cerebral palsy, learning disabilities and she has mental problems as well.

Since cerebral palsy is not a hereditary condition (Nelson & Grether, 1999), this might in fact be evidence of assumptions against parents with LD.

Apart from the above exceptions, most parents had never heard such assumptions directly expressed. The remainder of this super-ordinate theme considers assumptions perceived by the parents, rather than directly expressed assumptions.

#### *Children will be removed*

Parents identified a number of stereotypical assumptions that professionals might make. The primary<sup>34</sup> expectation parents had was that professionals would automatically want to remove their children. In one example, Alan discusses his concerns when social services became involved with his family:

Alan: It's as though we have mistreated Samuel, which we haven't. 'Right, if you do not keep to your appointment, you will be sent to prison' and everything, and I thought my gosh, you know. And I know the first stages would be your child would be taken into care.

Other parents expected professionals to remove their children because of stories told by their friends:

Georgia: I was worried a little, yeah, cos I been told things like off friends and I thought they [social services] could take the kids see and I worried... like they'll come in and they'll just take the kids.

---

<sup>34</sup> Primacy of result is based on theme's saliency, which considers both frequency and importance of a code (Buetow, 2010).

### *Unable to cope*

It appears that parents expected three key assumptions to be behind professionals' desire to remove their children. The most prominent expectation, discussed by eight parents, was that professionals would assume that they would be unable to cope with children. This expectation was seen in the following extracts from Tommy and Laura:

Tommy: Well, if you're talking about social services, I think they might think you shouldn't have kids at all, for one reason they think that you can't cope.

Laura: Donna [social worker], yeah, she thought I couldn't handle it to have a baby.

Esther proved an exception to this theme. She was aware that professionals might make this assumption, but never attributed it to professionals she worked with:

Esther: They've never like said, just cos I've got a disability would I be able to cope with Samuel. That's never occurred because we do our best with Samuel, and even though I've got a disability as well, that's never been an issue, no.

### *Child of parent with LD would be disabled too*

The second most prominent expectation was that professionals would think their children would automatically have LD too. Six of the parents considered this assumption, including Danielle:

Danielle: I think they guessed that Leanne gonna be and Spencer gonna be like me.

Interviewer: How like you?

Danielle: I think they think they're gonna have learning difficulties like me and be stupid.

Alan also wondered if professionals and the wider public would make that assumption:

Alan: Basically people in general... I would think they would say, 'Oh no, I wouldn't do that, because you know, you've got problems, you've got problems, you know, two thickoes don't make a right'.

### *Inability to learn*

The final assumption emerging for around half of the parents was that professionals would assume parents could not learn new skills. For instance, Fiona catalogued the things professionals thought she couldn't learn to do:

Fiona: They didn't think I'd be able to do the house, sort the kids out, do all the rent, pay the bills.

This expectation is potentially supported in that only one couple was offered a parenting class. This seems strange considering that parents' ability was often apparently questioned based on deficiencies in basic parenting skills. This could either reflect professional opinion that the parents would not benefit from such a course, or the lack of local resources available.

Parents' experience of treatment by professionals (influenced by assumptions)<sup>35</sup>

While the first over-arching theme considers parents' expectation of professionals' assumptions, the second theme considers professionals' actions, which may exemplify their assumptions. The perceived assumptions of Theme 1 might be influenced by parents' experience of professional actions, while conversely, the way parents perceive professional actions might be based on their pre-conceptions of professionals' assumptions. Thus, although the themes are inter-related, they remain distinct.

*Treated differently*

An almost universal experience for parents, was being treated differently to parents without LD. Joyce, for instance, felt services were nicer to other families:

Joyce: Well they're not doing the same way they're treating us, though, so I don't know what it's like, cos they're doing more better, helping more, nicer with it with other ones, but except for us two, and our family.

Most parents were clear that the differences in treatment and attitudes were specifically due to their LD:

Alan: I think, you know, even if we were able-bodied people, no problems, top-flight people, like some people are, I don't think big brother would have even said Boo to a goose. The system is maddening, isn't it, it's wrong.

---

<sup>35</sup> See section 3.2 for additional themes related to Super-ordinate theme 2.

Contrastingly, Esther rejected the idea that she was treated differently because of her LD, although she acknowledges this might be different without a pre-existing relationship with services:

Esther: I didn't really think much how they would treat us different because I think how they would treat us different if they have known us for a short period of time and they didn't know our personality. Then you would think 'Oh they would treat us different'.

Given this experience of being treated differently to other families, it could be assumed that parents attribute professionals' actions to the assumptions they make.

#### *Accusation of guilt*

An emotive issue for seven parents was the swift accusation of guilt by professionals following crises. For some, this occurred when children had made claims at school which were later shown to be untrue. Five other parents felt blamed for uncontrollable situations, such as unavoidable child illness. For instance, Alan described the reaction to his son's difficulty swallowing due to a physical disability:

Alan: Next day, we had a phone call, 'Oh you're being put on a child protection plan because you were trying to choke your child or something'.

For one family, this immediate presumption of guilt might have had more serious consequences:

Danielle: Once they accused me husband. Leanne got hold of this toy carrot... and she stick it up her bum. And the social worker called Tommy a child molester. Took her to the doctors and they said, no, Tommy ain't doing it, she doing it. They saw her holding the carrot and they saw her doing it. The social worker got told off from the doctor.

### *Paternalistic treatment*

The concept of paternalistic treatment resonated throughout parents' stories. Parents described being patronised, treated like children and made to feel stupid:

Tommy: They talk to Louise more downwards and that, as if she is a bit thick. In my opinion they talk to her like a little kid who doesn't know what she's on about.

A potential consequence of this paternalistic stand-point is that parents' voices are ignored, whether expressing concerns over their children's health or expressing their wishes. In one case, Joyce claims her wishes were ignored with regard to switching off her son's life support machine:

Joyce: They asked me if I wanted it turning off and I said no, but they just go and do it still. I said no, but... and they just gone and turned it off.

Two of the mothers had partners without LD. They noticed that professionals tended to discuss important information with their partner rather than them:



Interviewer: Are you happy with them talking to him instead of you?

Fiona: I think they should tell me things as well, yeah, rather than keeping me in the dark... They just think I don't know the situation.

Most of the parents felt excluded from the process by the lack of transparency of professionals. Parents felt decisions were made behind their back, using obfuscated decision-making processes. For parents fighting to maintain custody, this was incredibly frustrating:

Danielle: They ain't explained why she went into care and what we're doing wrong. They keep making excuses why... they keep saying different things. One that would say it was the house, one said it was the garden, then it would be mum's illness.

#### *Unrealistic demands*

The sense that professionals were setting unachievable targets was a powerful theme for half the parents. Parents felt their efforts could never be good enough, and that they were being set up to fail, having to meet higher standards than the rest of the population:

Danielle: One social worker said to me, you've got to have a house like the palace... they want us to have a house like a show house.

For other parents, every time they met a target, the goals changed, either because a new staff member had different ideas, or because professionals were looking for problems:

Greg: She [social worker] moaned the house was too hot, then when I changed it she moan the house was too cold. Yeah, you never got it right with her.

### *Impact of perceived assumptions and treatment*<sup>36</sup>

These negative experiences of working with professionals and the assumptions that parents perceive the treatment to be based on, had implications in two key areas: emotional impact on parents; and their interpersonal relationships with professionals and services.

#### *Emotional impact*

The emotional impact on parents was varied. The primary impact was anxiety and stress around the involvement of services:

Interviewer: Why would they have taken the kids?

Georgia: Cos Timmy went and told the school that we're hitting him when we weren't. So we were panicking... I didn't know if they'd judge me [because of my LD].

In two cases, fear verged on paranoia, certain that services are waiting for an opportunity to remove another child:

Tommy: I think that people is looking at us all the time now, saying they really can't cope and all that nonsense.

The second key impact on parents individually was the effect on their confidence. Seven parents admitted that the way professionals treat them,

---

<sup>36</sup> See section 3.3 for additional themes relating to Super-ordinate theme 3.

and the perceived assumption that they couldn't cope, had decreased their confidence:

Interviewer: So when you thought people would think you couldn't do it, did that affect you?

Danielle: Yes, I thought I couldn't do it and that's the reason I got put off a little bit and thought I couldn't cope myself.

Interviewer: Why do you think that was?

Danielle: It's people keep telling me I'm doing it wrong and that didn't help in the end.

Relatedly, paternalistic support seems to promote over-reliance on professionals, rather than confidence to make decisions:

Alan: So with our first social worker, we'd have to keep phoning her every two minutes, 'Can he have this? Can he have this?'

Similarly, when professionals or family members act in a way which assumes incompetence, the parent is denied an opportunity to learn:

Esther: When I went to peel chips or do anything, me dad wanted to take over, said 'Oh, I'll do it' and it's a bit like... no I can do it. They wanted to wrap me in cotton wool which I wouldn't have learnt and it would set me back and I had to be like no, I can do it.

Finally, perceived assumptions and experience of treatment has affected parents' sense of efficacy in battling against services. As an exception, one parent appeared energised to fight back:

Larry: That's one thing that I wouldn't ever do, let 'em take my child away. I will take 'em to court and then fight it, every single penny.

However, the more common impact was a sense of powerlessness and resignation to the decisions of social services, as exemplified by Tommy:

Tommy: There's no one gonna take them [social services] on, for one reason, if you take them to court, they gonna win. You see they got all the power and if they want to use all the power... I can't do nothing about it.

#### *Impact on relationship with services*

A number of parents expressed their future lack of trust in professionals. Perhaps Tommy expressed this most passionately in response to assumptions:

Tommy: They made me think I'll never trust the professionals. It's almost as if the professionals aren't there to help you at all, they're there to ruin your life. I would never trust the professionals.

In fact, for some, the perceived attitudes of the professionals made them want to disengage:

Fiona: I didn't want to talk to the other people [professionals] cos they're too higher up, it just made me feel like oh no where do I put myself.

Several parents were reluctant to speak up, in case it got them into trouble. For some, this meant they were reluctant to ask for help in case of being judged:

Fiona: All the time I was worried about it cos I don't like asking.

Interviewer: What might people have thought if you asked for help?

Fiona: If I had went to ask for help they probably would turn me away, not class me as a normal person.

Others feared disagreeing with professionals due to the potential activation of assumptions. Greg, for instance, suffered a crisis with his son as a consequence of not feeling able to voice opinions:

Interviewer: Did you tell them they were pushing too fast?

Greg: Well not really, but you did get a sense... but you dare not say nothing because you're not in agreement. But you did get the sense that they was pushing too fast.

Interviewer: You dare not saying anything?

Greg: Well, you feel like they'll feel that you're not gonna cope with Harry back in.

Some parents felt unable to speak up at all, in case their words were used against them:

Danielle: I let him [Tommy] do all the talking in meetings. I feel afraid if I open my mouth I getting confused. I might say something

to upset them and I don't want to upset them. I get confused, I say something, then they do twist it wrong.

Overall, many families are left using rhetoric of battling with services, rather than working together:

Alan: And she [psychologist] says you've had to fight for everything.

I said, well we have, you know, and we're still fighting now.

For three families, the impact of the treatment they received, led to more extreme consequences, such as ill health brought on by stress. When professionals refused to listen to Alan's concerns over his son's health, the delay was said to have left him brain damaged:

Alan: His brain is damaged he [Medical consultant] says, because he was born with it and it was really, really late to be picked up. I said yeah, by the people who wasn't listening to what I was saying. Yes, he said, exactly.

#### Parents' view of themselves and parenting<sup>37</sup>

Given that most parents did indeed attribute assumptions about parents with LD to professionals, it was interesting to consider whether these parents made assumptions about themselves.

##### *Subtheme 1: Assumptions about own ability*

When considering what it would be like to be a parent, some parents expressed worries, and some did not. For those who were concerned, it does not appear to be any different to the fears encountered by any new parent:

---

<sup>37</sup> See section 3.4 for additional themes relating to Super-ordinate theme 4.

Interviewer: What did you think it would be like to be a mum?

Georgia: I thought it would be a little bit hard, but I was alright.

In contrast to the assumptions they attributed to professionals, parents generally expected to cope well with parenting, and did not expect that their children would have learning disabilities:

Tommy: I like to be a dad and I felt up to the mark to be a dad.

Interestingly, a few parents were more likely to make assumptions about other parents with LD than about themselves. Greg discussed a woman with LD, who he assumed could not cope without the support of her more able husband:

Greg: She was having labour and she's on special needs. She did get worrying they gonna take her baby away... I suppose she knew she not gonna cope. But she has got a husband; he's not on special needs.

#### *Reaction to assumptions*

A further area which elucidated whether parents had internalised negative stereotypes, is their reaction to assumptions made about them. A number of parents reacted angrily to the assumption that they could not cope or explicitly stated that the assumptions were unfair:

Interviewer: Did the assessment feel good at the time?

Larry: It's not fair is it and that? But it's how they see it.

Interviewer: Do you think it's right?

Larry: No, not really. Everyone should have a chance.

The parents who reacted in this way tended to speak of their desire to prove people wrong, emphasised their right to be a parent and to battle against the system. While it would appear that these parents had not internalised assumptions about their ability to cope, half of the parents expressed a feeling of inevitability and/or acceptance that people would question their ability. This was the case for Greg:

Greg: It's always gonna happen anyway, cos you got special needs and you'll always have them [Social services] coming out anyway.

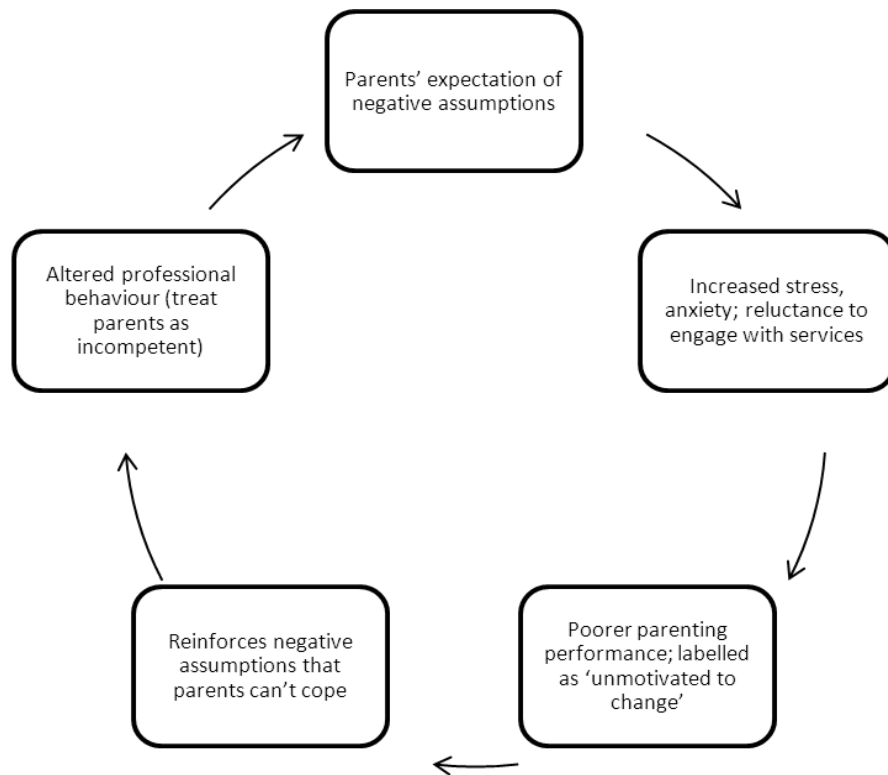
### **Discussion<sup>38</sup>**

Results suggest that parents are indeed aware of negative assumptions surrounding their role as parents, particularly the myths that they cannot cope, that their children will also be disabled and that they are unable to learn parenting skills. Parents attribute these assumptions to professionals where they seem consistent with professional behaviour. As a result, parents feel stressed, under-confident and unwilling to work with services. The temporal precedence of this relationship is not clear from the current research (whether pre-conceptions of assumptions shape how parents experience interactions with professionals, or whether professional behaviour leads to the attribution of negative assumptions). However it is possible that a cycle of negative interaction and mutual suspicion is maintained (See Figure 4).

---

<sup>38</sup> See section for 4.2 for discussion of additional themes.





*Figure 4: Possible cycle of negative interaction between parents and professionals.*

#### *Parents' expectation of assumptions*

Parents were generally aware of stigma associated with their LD and perceived that professionals made stereotypical assumptions about them. This is consistent with recent findings that people with LD are aware of and affected by stigma (Jahoda & Markova, 2004), rejecting Todd's (2000) notion that their level of cognitive development protects them from stigma.

Parents were clear on the specific assumptions professionals might make about them, which closely relate to myths identified by Espe-Scherwindt and Crable (1993). These myths have been largely ignored since this article, but the current research suggests they still have a role in maintaining negative attitudes towards parents with LD, which have been

consistently shown to exist in a proportion of professionals (Aunos & Feldman, 2002).

With a few notable exceptions, parents had not experienced direct propagation of these attitudes from professionals. This is unsurprising given the prevailing orthodoxy of normalisation, but does not exclude the existence of more subtle prejudice, in line with the social desirability to appear accepting of parents with LD (Rattazzi & Volpato, 2003).

An interesting contradiction in this theme is that, when initially asked whether they expected professionals to make guesses about them, two parents replied in the negative. It was only in discussing their current treatment that they made links between the assumptions made by professionals and parental LD. This might suggest that parents had difficulty hypothesising other people's feelings without the context of current experiences. It could also reflect Davies and Jenkins's (1997) hypothesis that people with LD may be aware of stigma, but not the discourse surrounding the experience.

#### *Parents' experience of treatment by professionals*

With one exception, parents felt they were treated differently by professionals because of their LD. The subtext of this statement is that parents feel that professionals' behaviour is driven by their assumptions. Parents distinguished between helpful or unhelpful support, linked to the absence or presence of negative attitudes. This is in keeping with Deeley's (2002) finding that different professional behaviour could be predicted by their 'normalising' or 'paternalistic' attitudes.

The unhelpful behaviours described by the parents can be seen in the context of discrimination, although this is a subjective account from parents of a potentially cyclical process. For instance, several parents experienced blame for uncontrollable events. This may represent a stereotypical attribution, whereby professionals operating on negative assumptions are more likely to assign cause of events to the object of stereotype: thus cause for child ill-health would be falsely attributed to parental LD rather than attributed to external causes.

In other examples, professionals are described by parents as being intentionally obstructive, setting unrealistic demands and not listening. This could be understood through Azjen's (1985) theory of planned behaviour. If the behaviour in question for professionals is whether to proactively support parents, three factors would affect their intention to do so: their attitude towards the behaviour; social norms surrounding the behaviour; and belief about control over the behaviour (i.e. whether they are equipped to perform the behaviour). If, then, a professional believed that even effective support is unlikely to yield effective results, this would affect their attitude towards supportive behaviour such that they are less likely to engage in supportive acts. This intention could be moderated by social norms which would condemn that choice. However, in this situation, that is not necessarily the case, as attitudes against people with LD as parents are sufficiently strong to negate ideals of inclusion. When you add in the fact that professionals feel undertrained and underequipped to support parents (Ward & Tarleton, 2007) this may result in some professionals not intending to support parents in the most effective way possible.

However, while parents may indeed be receiving discriminative treatment, it is also possible that they are labelling treatment as discriminative in expectation of stigma. Modified labelling theory, for instance, would posit that once a person is given a stigmatising label (e.g. LD), they become cognitively primed to encounter devaluation and discrimination (Link, 1987). They may respond behaviourally (through secrecy or withdrawal) in anticipation of rejection or discrimination, without such rejection actually existing (Link et al., 1989). In the current situation, it could be that parents labelled with LD, being aware of the stigma surrounding their status, are more alert to discriminative behaviour. They may attempt to mask their difficulties or disengage with services in anticipation of discrimination, both of which behaviours would lead to increased concern from services and maintenance of negative assumptions.

#### *Impact of perceived assumptions and treatment*

Regardless of the motivations behind professionals' actions, parents' perception of assumptions impacted both personally and on their relationships with professionals. Firstly, many parents expressed anxiety and stress as a result of their treatment. This is predicted when a group feel stigmatized (Miller, 2004). However, the implication is that this might detrimentally affect their parenting. Feldman's (2002) model of parenting adequacy suggests that stigma impacts on parenting through its effects on parental mental health. This would represent a worrying cycle of negativity, in which assumptions about parental inadequacy, ultimately confirm parental inadequacy, due to the stress of the associated stigma.

As predicted by Corrigan et al. (1999), the effect of negative assumptions on parents' self-efficacy varied widely, with some feeling completely unable to influence their own future, while others felt energised and empowered to fight back.

Equally problematic is the impact of assumptions on parents' professional relationships. The positive impact of support and intervention has been consistently shown for parents with LD. Improvements in knowledge, parenting style, child behaviour and placement outcome have all been demonstrated following training and intervention by services (Wade et al., 2008). Equally, the individual impact of positive, competence-promoting support (Tucker & Johnson, 1989) and family-centred professional interactions (Wade et al., 2007) on satisfaction with support for parents with LD has been noted. Given that satisfaction with support is directly related to positive mother-child interactions (Feldman et al., 2002), the importance of maintaining positive relationships with supporting professionals is clear. Several of these parents, however, have lost trust in professionals, and considered disengaging with services. These parents are not portraying a general reluctance to engage with professionals. They are specific in their distrust of certain professionals based on their perceived attitudes. However, this still presents a risk for parents: any sign of reluctance to engage with services is likely to be taken to signify unwillingness to change and unwise decision making (Aunos & Feldman, 2002), thus perpetuating the cycle of negative assumptions.

### *Parents' view of themselves and parenting:*

The extent to which assumptions affected parents' own views of themselves and parenting was varied. While a few parents appeared to have internalised the assumption that they would not be able to cope as a parent, the majority had not, indicating a belief that they could succeed and had the right to do so. This matched the variation in parents' response to assumptions: indignant or resigned. This offers a useful perspective on the idea of self-stigmatization in parents with LD. This phenomenon has been extensively researched in mental health populations (Corrigan & Watson, 2006), but less so in LD populations. The variation in response would be predicted by a model of self-stigmatization, however, which predicts individual differences based on underlying self-esteem and the extent to which an individual identifies with the stigmatized group (Watson et al., 2007). The parents in this study tended to identify themselves strongly with other groups, such as single parenthood or being physically disabled. Given that these groups experience a lesser degree of stigmatization, this might serve a protective function for parents in terms of the extent to which they self-stigmatize due to their LD.

### *Clinical Implications<sup>39</sup>*

Overall, these results offer the first confirmation that parents with LD are indeed aware of and reacting to perceived assumptions about their ability, which relate to common myths identified nearly twenty years ago. They suggest that UK government policy has not gone far enough in reducing stigma around the diagnosis of LD, and ties into the growing evidence that parents with LD are discriminated against in Child Protection Proceedings.

---

<sup>39</sup> See section 4.5 for extended consideration of clinical implications of research.

The idea that parents and professionals are locked in a cycle of negative interaction offers multiple avenues for change. From a professional perspective, training could highlight false evidence behind myths about parents with LD, with the aim of changing prevailing attitudes. However, regardless of underlying assumptions, this study highlights the importance of professionals behaving in a way which is empowering for parents, and therefore less likely to activate their expectation of assumptions<sup>40</sup>. Equally, given the inherent power imbalances in parents' accounts of working with services, the need for independent advocates for parents is emphasised. When a perceived power imbalance is equalised, the impact of stigma is likely to be reduced. All of these scenarios would be predicted to reduce parental stress and its subsequent impact on parenting adequacy and to maximise parental engagement with services, making it possible to provide more effective support in maintaining family units.

#### *Critique of study methodology<sup>41</sup>*

The aim of the current study was to explore the impact of inaccurate professional assumptions about parents with LD, in terms of parents' subjective perception of assumptions and treatment. The study did not seek to elicit professionals' assumptions about parents with LD, which may need to be re-addressed in future as the prevailing orthodoxy regarding parents with LD develops.

The use of interview methods with people with LD is both a strength and a weakness of the current design. The tendency of people with LD to give inconsistent or contradictory responses during interviews has been

---

<sup>40</sup> See section 4.6 for Good Practice Guidelines

<sup>41</sup> See section 4.3 for an extended critique of the study.

frequently noted (McIver & Meredith, 1998), as has the possibility that they may prove inarticulate interview subjects, who struggle to conceptualise abstract concepts (Booth & Booth, 1993). It has therefore been argued that interview data from people with LD should be interpreted with caution (McKensie et al., 1999). However, through a structured analytic process, it has been possible to incorporate inconsistencies within the analysis, by acknowledging and exploring the reasons behind any contradictions.

Qualitative research runs the risk of presenting findings based on the researcher's pre-conceptions, whilst overlooking alternative conclusions (Cohen et al., 2007). This threat to reliability was limited by acknowledging the researcher's opinion at the outset, keeping an audit trail of decision-making processes and keeping a reflective diary<sup>42</sup>. Analysis of the interview data also remained closely tied to parents' accounts, and although some interpretation was required, the results of the analysis remained relatively concrete. This may reflect parents' own concrete representations of themselves and others. Additionally, given the small sample size and homogeneity of the group, care should be taken in assuming transferability of findings to all parents with LD.<sup>43</sup>

### *Future Directions*

Whether or not unhelpful professional behaviour is in fact discriminatory, the fact remains that the parents themselves experience stigma. Feldman (2002) hypothesises the impact of stigma on parental adequacy, however no research has confirmed this proposed relationship, mediated by its

---

<sup>42</sup> See section 5 for a critical reflection on the research process, with extracts from the reflective diary.

<sup>43</sup> See section 4.4 for extended discussion of transferability of findings.



impact on mental health. The results of the current research suggest that this might be important to consider.

Given the individual differences noted amongst professional attitudes, it would be interesting in future research to focus on what factors might influence the nature of professional support. Based on previous research, a number of factors might be important to consider: length of time in service, availability of resources, confidence in abilities, differences between child services and LD services, and differences between health and social care professionals.

### *Conclusion*

In summary, the current research provides an initial basis for research investigating the impact of outdated assumptions on parents with LD. Parents are not only aware of the existence of such assumptions, but are often greatly affected by them, attributing unhelpful treatment by professionals to the assumptions they make. Given the potential impact of these assumptions and treatment on parents' self-esteem, mental health and willingness to engage with services, this has important implications for the ways professionals interact with parents with LD in the future.

## References

- Abraham C., Gregory N., Wolf L. & Pemberton, R. (2002) Self-esteem, stigma and community participation amongst people with learning difficulties living in the community. *Journal of Community and Applied Social Psychology* 12, 430–443.
- Aunos M. & Feldman M.A. (2002) Attitudes toward sexuality, sterilization, and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disability* 15, 285-296.
- Aunos M., Goupil G. & Feldman M. (2008) Mothers with intellectual disabilities who do or do not have custody of their children. *Journal on Developmental Disabilities* 10(2), 65-79.
- Ajzen I. (1985). From intentions to actions: A theory of planned behavior. In: *Action Control: From Cognition to Behavior* (Eds J. Kuhl & J. Beckmann), pp. 11-39. Springer, Heidelberg.
- Ajzen I., & Fishbein M. (2004) The influence of attitudes on behavior. In: *Handbook of Attitudes and Attitude Change: Basic Principles* (Eds D. Albarracín, B. T. Johnson & M. P. Zanna), pp. 173-221. Erlbaum, Mahwah.
- Booth T. & Booth W. (1996) Sounds of silence: narrative research with inarticulate subjects. *Disability and Society* 11(1), 55-69.
- Booth T. & Booth W. (2004) *Parents with learning difficulties: child protection and the courts, a report to the Nuffield Foundation on Grant No. CPF/00151/G*. Sheffield University: Department of Sociological Studies.
- Booth T., Booth W. & McConnell D. (2005) The prevalence and outcomes of care proceedings involving parents with learning difficulties in the family courts. *Journal of Applied Research in Intellectual Disabilities* 18, 7-17.
- Bradley R., Toft S., & Collins G. (2000) Parenting assessments. *Learning Disability Practice* 2(5), 9-11.

- Braun V. & Clarke V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101.
- Buetow S. (2010) Thematic analysis and its reconceptualization as 'saliency analysis'. *Journal of Health Services Research & Policy* 15(2), 123-125.
- Cleaver H., & Nicholson D. (2003) *Learning disabled parents and the Framework for the Assessment of Children in Need and their Families*. Royal Holloway, University of London, London
- Cohen L., Manion L. & Morrison K. (2007) *Research Methods in Education* (6th ed.) Routledge, London.
- Corrigan P.W., Faber D., Rashid F., & Leary M. (1999) The construct validity of empowerment among consumers of mental health services. *Schizophrenia Research* 38, 77-84.
- Corrigan P.W., Larson J.E., & Rusch N. (2009) Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry* 8(2), 75-81.
- Corrigan P.W., Watson A.C., & Barr L. (2006) The self-stigma of mental illness: Implications for self-esteem and self-efficacy. *Journal of Social and Clinical Psychology* 25(8), 875-884.
- Dagnan D. & Waring M. (2004) Linking stigma to psychological distress: testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy* 11, 247-254.
- Davies C.A. & Jenkins R. (1997) 'She has different fits to me': How people with learning difficulties see themselves. *Disability and Society* 12(1), 95-109.
- Deeley S. (2002) Professional Ideology and learning disability: an analysis of internal conflict. *Disability and Society* 17(1), 19-33.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. The Stationary Office, London.

- Department of Health (2007). *Good Practice Guidance on Working with Parents with a Learning Disability*. The Stationary Office, London.
- Department of Health (2009). *Impact Assessment - Valuing People Now 'making it happen for everyone'*. The Stationary Office, London.
- Espe-Scherwindt M. & Crable S. (1993) Parents with intellectual disabilities: moving beyond the myths. *Topics in Early Childhood Special Education* 13, 154-174.
- Evans D., McGuire B., Healy E., & Carley S. (2009) Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research* 53(11), 913-921.
- Feldman M.A. (2002) Parents with intellectual disabilities and their children: impediments and supports. In: *Ethical dilemmas: Sexuality and developmental disability* (Eds. D. Griffiths & P. Federoff), pp. 255-292. NADD Press, Kingston, NY.
- Feldman M., Varghese J., Ramsay J., & Rajska D. (2002) Relationship between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 15, 314-323.
- Fereday J., & Muir-Cochrane E. (2006) Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods* 5(1), Article 7.
- Goodinge S. (2000) *A jigsaw of services: Inspection of services to support disabled adults in their parenting role*. Social Services Inspectorate: Department of Health, London.
- Guba E.G. & Lincoln Y.S. (1994) Competing paradigms in qualitative research. In: *Handbook of Qualitative Research* (Eds N.K Denkin & Y.S. Lincoln), pp. 105-107. Sage, CA.

- Jahoda A. & Markova I. (2004) Coping with social stigma: people with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research* 48, 719–729.
- Link B.G. (1987) Understanding labeling effects in the area of mental disorders: an assessment of the effects of expectations of rejection. *American Sociological Review* 52, 96–112.
- Link B.G., Cullen F., Struening E., Shrout P., & Dohrenwend B. (1989) *American Sociological Review* 54, 400-423.
- Madill A., Jordan A., & Shirley C. (2000) Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology* 91(1), 1-19.
- McGaha C.G. (2002) Development of parenting skills in individuals with an intellectual impairment: An epigenetic explanation. *Disability & Society* 17, 81-91.
- McGaw S., Scully T. & Pritchard C. (2010) Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. *Child Abuse and Neglect* 34(9), 699-710.
- McIver S. & Merideth P. (1998) There for the Asking. *Health Service Journal*, 26-27.
- McKenzie K., Murray G. & Matheson E. (1999) An examination of importance of aspects of services to people with a learning disability. *British Journal of Learning Disabilities* 27, 25-9.
- Miller C. (2004) Social psychological perspectives on coping with stressors related to stigma. In: S. Levin & C. van Laar (Eds.), *Stigma and group inequality: Social psychological perspectives* (Eds S. Levin & C. van Laar), pp. 21-44. Lawrence Erlbaum, NJ.
- Nelson K.B. & Grether J.K. (1999) Causes of cerebral palsy. *Current Opinion in Pediatrics* 11, 487-91.

- Paterson L., McKenzie K. & Lindsay B. (2012) Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 25, 166–176.
- Pixa-Kettner U. (1998) Parents with intellectual disability in Germany: Results of a nation-wide study. *Journal of Applied Research in Intellectual Disabilities* 11(4), 355-364.
- Pixa-Kettner U. (2008) Parenting with intellectual disability in Germany: Results of a new nationwide study. *Journal of Applied Research in Intellectual Disabilities* 21, 315-319.
- Rattazzi A.M.M. & Volpato C. (2003) Social desirability of subtle and blatant prejudice scales. *Psychological Reports* 92(1), 241-250.
- Robb M. (2004) Exploring fatherhood: masculinity and intersubjectivity in the research process. *Journal of Social Work Practice* 18(3), 395-406.
- Tarleton B., Ward L. & Howarth J. (2006) *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. Baring Foundation, London.
- Tarleton B. & Ward L. (2007) Parenting with support: the views and experiences of parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 4(3), 194-202.
- Thomson M. (1998) *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain c.1870–1959*. Clarendon, Oxford.
- Todd S. (2000) Working in the public and private domains: staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research* 44, 600-620.
- Tucker B. & Johnson O. (1989) Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization* 48, 95-107.

- Tymchuk A. & Andron L. (1990) Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse and Neglect* 14, 313-23.
- Wade C., Llewellyn G. & Matthews J. (2008) Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* 21, 351-366.
- Ward L. & Tarleton B. (2007) Sinking or swimming? Supporting parents with learning disabilities and their children. *Learning Disability Review* 12(2), 22-32.
- Watson A.C., Corrigan P.W., Larson J.E., & Sells M. (2007) Self-stigma in people with mental illness. *Schizophrenia Bulletin* 33, 1312-1318.
- Wechsler D. (1997) *Wechsler Adult Intelligence Scale—3rd Edition (WAIS-3)* Harcourt Assessment, San Antonio, TX.
- Willig C. (1999) Beyond appearances: a critical realist approach to social constructionism. In: *Social constructionist psychology: a critical analysis of theory and practice* (Eds D.J. Nightingale & J. Cromby), pp. 37-51. Open University Press, Buckingham.
- Woodhouse A., Green G. & Davies S. (2001) Parents with learning disabilities: service audit and development. *British Journal of Learning Disabilities* 29(4), 128-32.

## Extended Paper



## **Extended Paper**

### **Extended Introduction**

#### **1.1 Background Information**

##### *1.1.1 Learning Disability Definition*

The definition of what constitutes a Learning Disability (LD) is a somewhat unstable concept, which has been constantly evolving since the second half of the twentieth century (McConnell & Llewellyn, 2002). For instance, the American Association on Mental Retardation has altered its definition on six occasions since 1950 (Luckasson et al, 1992). The changes to the definition included the lowering of the intelligence quotient (IQ) ceiling from one to two standard deviations below the mean (MacMillan, Gresham & Siperstein, 1993) and the introduction of the criterion of adaptive behavioural deficits.

The current UK definition of LD, as described by the Department of Health (2001), encompasses three key factors:

- “• A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development” (p.14).

The current UK definition centres upon standardised intelligence scores from tests such as the Wechsler Adult Intelligence Scale – Fourth Edition (WAIS IV, 2008). The common cut-off used to determine a classification of learning disability is an IQ of below 70, which is based on a score two standard deviations below the mean IQ of the general population (Crawford, Gray & Allan, 1995). This score alone is not sufficient to determine a person’s eligibility for LD services, however, as most services incorporate an assessment of the person’s adaptive behaviour and ability to function in the community independent of support (British Psychological Society, 2001).

In recognition that the term ‘learning disability’ in no way describes a homogeneous group, individuals are categorised as having either a mild

(IQ: 55-70), moderate (IQ: 40-55) or severe (IQ: below 40) learning disability. It is estimated that of the LD population in the UK, 80% have a mild LD, 12% have a moderate LD and 7% have a severe LD (Carr & O'Reilly, 2007).

Due, in part, to the evolving nature of the definition of LD, studies investigating parents with LD have used a variety of criteria to limit inclusion in research. Early research often favoured previous institutionalisation as a sampling criterion (e.g. Floor, Baxter, Rosen & Zisfein, 1975). More recently, researchers have primarily used one of two methods to define their sample. Firstly, a definition based on IQ scores alone has been used (e.g. Feldman, 1994). However the actual IQ used to define LD in these parents has varied enormously, with some studies using a cut off of  $69 \pm 5$  (McGaw, Scully & Pritchard, 2010), while others increase the IQ boundary to as high as 85 (Keltner, Finn & Shearer, 1995). This has the obvious drawback that it incorporates parents of potentially vastly differing abilities, who may or may not be representative of an LD population. Secondly, a so-called 'social systems' definition of LD (Mercer, 1973) is often used, whereby a person is said to meet the inclusion criteria if they are identified as having a learning disability by key figures, often service providers (e.g. Llwellyn, McConnell, Cant & Westbrook, 1999). Although studies adopting the latter definition avoid the problem of unavailable data regarding parents' cognitive ability, they run the risk of ignoring a population of parents with LD, who are coping sufficiently well without specialised support to essentially remain invisible to services.

Since the current study seeks to explore parents' views of professionals particularly with regard to the label of having a learning disability, a more socially constructed definition of learning disability will be used, in that inclusion will be dependent on their accessing specialist LD services. However, where available, results from previous WAIS assessments will be accessed in order to consider the true representativeness of the sample.

It is important to note that specialist LD teams may, in fact, accept those with a borderline LD (individuals with an IQ between 70-85) into the service. This can be for a variety of reasons, such as the absence of a

cognitive assessment, or a clear need that is best served by a specialist LD service despite an IQ over 70. Thus, it is possible in the current study that parents with a borderline LD could be included. It might initially seem illogical to include in a study of parents with LD, individuals who would be precluded from that definition based on their IQ. However, the choice is justified by the fact that IQ alone is not predictive of parenting ability or responsiveness to parenting interventions until IQ falls below 55 (Tymchuck & Feldman, 1991). It is therefore thought that a group of parents with IQ between 60 and 80 is more likely to represent a homogenous group of people who might encounter difficulties in their parenting, but would have a chance to raise their child successfully at home. Additionally, those with borderline LD constitute the majority of recipients of specialist parenting services (McGaw, 1996; Llewellyn & McConnell, 2002) and may therefore have experienced a similar level of stigma regarding the label of 'learning disability', regardless of their exact IQ.

#### *1.1.2 Learning Disability Terminology*

Throughout the current research, the term 'people with learning disabilities' or 'parents with learning disabilities' is used. This is the current term in common use in the UK to represent the group of people defined above. This has superseded previously used terms in the UK, such as 'mental handicap'. The terms used for this population vary worldwide, with research from the US still favouring 'mental retardation', while in Australian research, 'intellectual disabilities' and 'developmental disabilities' are used. For the purposes of the current research, where any of these terms occur in the research, they will be replaced by the term 'learning disabilities'.

Interestingly, advocates for people with LD have expressed a strong preference for the term 'learning difficulty' to be used, due to the lingering stigma associated with the term 'learning disability' (Walmsley, 2001). In order to avoid confusion with the definition of specific learning disorders, such as dyslexia and dyspraxia, this recommendation will not be adopted in the current research. However, this raises an important issue related to the stigma that the label of 'learning disability' carries with it, which can lead to

isolation, bullying, and differences in treatment by schools, health and social professionals (Ho, 2004).

### *1.1.3 Prevalence of parents with Learning Disabilities*

There are no reliable estimates of the prevalence of parents with LD in the UK. The population of mothers and fathers with LD has been placed anywhere between 60,000 and 250,000 (McGaw, 1997) and 23,000 and 250,000 (Department of Health, 2007), although even the higher figure has the potential to be a severe underestimate. Around the world, an estimate was established by Mirfin-Veitch et al. (1999), using capture-recapture techniques, of 2.5 families per 1000. Based on US Census information, Barker and Maralani (1997) estimated that parents with LD made up 5% of the 7 million disabled parents in the US.

Establishing accurate population sizes of parents with LD has proved difficult for a number of reasons, the foremost of which is perhaps the lack of consistency of definition of LD as detailed above. This has led to the situation in which people with 'borderline' LD, who are estimated to represent the largest category within parents with LD, are sometimes counted within prevalence statistics and sometimes not (IASSID, 2008). Other potential reasons for the wide variance in prevalence estimates might include: families with LD parents remaining 'invisible' to services; the fragmented nature of services; and poor record keeping (Booth & Booth, 2004).

## **1.2 Perspectives about people with LD as parents**

### *1.2.1 Historical perspectives*

The eugenics movement had a heavy influence in dictating public opinion towards people with LD during the first half of the twentieth century, and is likely to have had a more lasting legacy in terms of persisting attitudes and even its impact on social policy. In the context of the aftermath of the Boer War, people with LD (at the time distinguished into categories of 'idiots', 'imbeciles' and the 'feeble-minded'), represented one of the most pressing social threats in the UK (Cleaver & Nicholson, 1997).

In 1901, Arnold White, "an increasingly pessimistic social Darwinist and early eugenicist", published figures in his article 'Efficiency and Empire' stating that 6 out of every 10 recruits from industrial cities were fundamentally unsuitable for military service, with prominent figures claiming that the British population was in a state of irreversible and mental degeneration (Soloway, 1995). With a government-instigated survey estimating the number of mental defectives in England and Wales to be 149,628, the 1913 Mental Deficiency Act was passed by an overwhelming majority of 358 to 15 (Thomson, 1998). The act allowed for the compulsory and permanent segregation of adult mental defectives, and is regarded by some as the only instance in which British Social Policy was primarily influenced by the eugenics movement (Harris, 1993).

After the publication of the (Wood) Report of the Interdepartmental Committee on Mental Deficiency in 1929, which highlighted that the mentally defective population was far higher than previously thought, a new strategy was called for. Mounting evidence was being produced which apparently confirmed the heritability of mental deficiency, including Goddard's (1912) Mendelian recessive theory. Despite obvious flaws in his methodology (he often diagnosed mental deficiency in ancestors of his subjects solely through photographs), his results were generally accepted as proof of heritability (Smith & Wehmeyer, 2012). Similarly, claims were made and embraced stating that mental defectives were likely to have twice as many children as the normal population and were inextricably linked with delinquency, crime, alcoholism, prostitution and the spread of venereal disease (Barker, 1989).

With this 'scientific' research as a backdrop, and with the United States Supreme Court officially recognising the legality of involuntary sterilisation (Buck vs Bell, 1927), a UK governmental report (the Brock Report) published in 1934, concluded that sterilisation of mental defectives was indeed justified, since these individuals were not fit or suitable to be parents. A sterilisation law was never in fact passed in the UK, in part due to the raising of issues of civil liberties; however the fear associated with people with LD reproducing had by then become ingrained in public attitudes, with lasting effect (Macnicol, 1989).

Although eugenic thinking began to diminish during the 1940s and 1950s, the ideas retained some influence, and voluntary sterilisations continued throughout the 1950s and 1960s (Reilly, 1991). People with LD remained segregated from the normal population, either in special 'communities' or large-scale institutions and the viewpoint at the time remained that people with LD were ineducable and irredeemable (Mazumdar, 1991). In fact, people with LD were not entitled to any kind of education in the UK until 1970.

### *1.2.2 Inclusion movement and current government policy*

The ideas of normalisation and inclusion in the 1970s and 1980s proved a key influence in changing the course for people with LD. These were principals which advocated "making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life and society" (Nirje, 1980, p. 33). Research had begun to demonstrate that learning outcomes of people with LD could be improved, and that behavioural patterns could change (e.g. Rice, 1968). Simultaneously, UK government policy was advocating the movement of people with LD out of institutions, and into community-based care (Department of Health & Social Security, 1971).

More recently, the rights of people with LD to participate in all aspects of life, including sexuality and parenthood, are increasingly being recognised, and government policy has reflected this in two key documents: Valuing People (2001) and Good Practice Guidance on Working with Parents with a Learning Disability (DoH, 2007).

The 2001 'Valuing People' White Paper (DoH) is recognised as the first UK policy statement which acknowledges the existence of people with LD who are also parents, in fact proclaiming their right to marry and have a family, with adequate support to be provided to assist them in maintaining their family unit. The document acknowledges the inconsistency and underdeveloped nature of services for these parents, and urges Social Services to work in partnership with parents to provide them with effective support. However, it laid out no guidance or incentive for these aims to be met (Booth, 2003). A review of the success of Valuing People was

undertaken in 2005, demonstrating that the document had had limited impact on the lives of people with LD (DoH, 2005).

'Good Practice Guidance on Working with Parents with a Learning Disability' was issued by the Department of Health & Department for Education & Skills (2007), aiming to highlight a number of important aspects of practice for both children and adult services to support parents effectively. These included: greater collaboration between professionals and services; a focus on strengths as well as weaknesses during assessments; access to long-term support where necessary; and the provision of clear and accessible information and communication. All of these recommendations are made on the basic assumption that the best interest of the child is served by supporting their parents to care for them at home. The guidance stresses the importance of refraining from making assumptions about the capacity of parents to successfully raise children, or their capacity to learn new skills. Interestingly, it was acknowledged in a response to criticism to the Joint Select Committee on Human Rights, that the guidance had only been disseminated to professionals within adult LD services and not professionals working in children's services (Ministry of Justice, 2009).

Despite the emergence of UK government policy demanding changes to service provision and practice to more effectively support parents with LD, the reality of service provision appears to fall short of meeting parents' needs. A national review of services by the Social Services Inspectorate (Goodinge, 2000) found that parents were being negatively impacted by a 'professional knows best' culture, in which professionals displayed a lack of knowledge, a hypersensitivity to risk and paid insufficient attention to issues of equality. In addition, parenting assessments were found to be of poor quality, eligibility for services was described as restrictive and services were generally fragmented in nature. Finally, it was felt that decisions regarding the removal of children from parents with LD were being made on the basis of 'innappropriate or inadequate information' (p.6).

There has been little research investigating the state of affairs for parents with LD since the implementation of the *Good Practice Guidance* (2007).

### *1.2.3 Myths about parents with LD*

The myths presented by Espe-Scherwindt and Crable in 1993 precede major changes in governmental policy and procedures not just in the UK, but worldwide. There has been very limited research on the presence or absence of these assumptions in the aftermath of these changes. However, 'Healthy Start' a government-funded organisation in Australia, founded in 2005, which aims to promote good practice working with parents with LD, currently offers a summary of 'Common stereotypes about Parents with Intellectual Disabilities' (Parenting Research Centre, 2010). It includes not only the four myths described above, but also the following assumptions: parents with LD will raise children in single-parent families; children of parents with LD will be socially isolated and brought up in poverty; children of parents with LD would be better off with another family; and children of parents with LD will feel ashamed of their parents.

This policy document suggests that these stereotypes are still current and prominent in the lives of parents with LD, an idea which is echoed by an international special interest group (IASSID, 2008) focussing on the challenges faced by parents with LD, who noted that the first and foremost challenge they face is that:

"statutes and "expert opinion" give legitimacy to the widespread, prejudicial, and empirically invalid assumption that parents with intellectual disabilities do not have the capacity to raise children" (p.255).

### *1.2.4 Evidence contradicting myths about parents with LD*

Although early research revolved around supporting and propagating such myths, influenced perhaps by the lingering eugenic agenda, extensive recent research has shown that there is little empirical evidence to support such assumptions.

1. Parents with LD won't be able to learn parenting skills: In the first review of its kind, Feldman (1994) examined 20 studies with a total of 190 participants, investigating the efficacy of parent training interventions for parents with LD. Overall, 96% of the parents involved



demonstrated improvements in at least one skill area, although there was limited evidence available about the impact of these changes on child outcomes.

In an updated review from 2008, Wade, Llewellyn and Matthews discovered only seven additional peer-reviewed studies evaluating parenting interventions published subsequent to Feldman's (1994) review. Building on early evidence, all seven studies emphasised that positive changes in parents' behaviour and knowledge occurred following training. The skills under assessment included basic child-care skills (e.g. cleanliness, feeding and managing illness), hazard awareness, parent-child interactions and play skills. However, unlike previous studies, six of these seven studies incorporated a follow-up period, ranging between one month and two years, all of which suggested that the majority of parents maintained their new skills and abilities over the medium- to long-term (e.g. Feldman, Ducharme & Case, 1999).

2: Children of parents with LD will inevitably be disabled: Research investigating the truth behind this myth comes in two parts. Early research (prior to the 1980s) focussed on dispelling the eugenic principles that 'breeding' between people with LD would produce offspring of decreased intelligence, risking the degeneration of the human species. This was clearly proved to be a false theory, since, on average, children of parents with LD have significantly higher IQs than their parents, and the majority in fact display average intelligence (e.g. Mickelson, 1947; Shaw & Wright, 1960; Scally, 1973).

Later research investigated more complex outcomes in terms of child development. In a comparison of developmental status of 70 children of mothers with LD and 32 children of mothers without LD, but matched for factors such as age and race, 42% of the former group were developmentally delayed, compared to only 12% in the control group (Kelter, Wise & Taylor, 1999). Similarly, Feldman, Leger and Walton-Allen (1997) compared 25 children of mothers with LD, to 20 children of mothers without LD, all from similar low-income areas. They found that, on average, the group born to mothers with LD performed less well on

measures of IQ, reading, and problematic behaviour. However, in both studies, the range of results varied considerably, with many children performing well in school and exhibiting no difficulties.

Although it appears that children of parents with LD are more at risk of developmental difficulties, it is not inevitable, and it suggests that other factors than IQ alone must be taken into account when considering child outcomes and parenting performance.

3: Parents with LD will have an inordinate amount of children: The limited recent studies which have addressed this question have shown unequivocally that parents with LD do not tend to have a large number of children. A German study to establish prevalence of parents with LD, found that of 969 parents, they had, on average, only one child per family (Pixa-Kettner, 1999).

4. Parents with LD will be unable to provide adequate care: Research into parental adequacy in people with LD has employed various techniques over the years, beginning with professional observation and opinion (e.g. Mickleson, 1947) and developing into more objective methods, such as standardized assessments and behavioural checklists (e.g. Keltner, 1994; McConnell, Llewellyn, Mayes, Russo & Honey, 2003). Attempts to determine the impact of parental IQ on parental adequacy have painted a mixed picture, demonstrating that it is very difficult to generalise parental difficulties in such heterogeneous group, and emphasising the importance of assessing each case individually (McConnell, Feldman, Aunos & Prasad, 2010). What does seem clear, however, is that there is no systematic link between parental competence and IQ, until IQ falls below 55 (Tymchuk & Andron, 1990).

Interestingly, when adult children of parents with LD are interviewed about their childhood, the vast majority report positive feelings of love and affection towards their parents (Booth & Booth, 2000) and maintain warm and loving relationships with them (Faureholm, 2006). The most difficult part of life reported by these children was in fact the stigma and subsequent treatment related to having a parent with LD.

As well as the idea that parents with LD will provide inadequate care, incorporated into this myth is the presumption that parents with LD are frequent perpetrators of child abuse or intentional neglect (McConnell, Llewellyn & Bye, 1997). In fact, abuse is very rare among parents with LD, more so than in the general population (McConnell, Llewellyn & Ferronato, 2000; Glaun & Brown, 1999). Unintentional neglect or failure to protect children from abuse by others is the most common reason for child removal (Booth & Booth, 2004).

#### *1.2.5 Professional attitudes towards sexuality and parenting in people with LD*

Following the emergence of principles of normalisation in the 1970s, a number of studies sought to examine the attitudes of professionals and carers regarding sexuality and parenting in people with LD. A 2002 review (Aunos & Feldman) highlighted numerous studies which found evidence of disapproving and conservative attitudes in direct care staff (e.g. McCabe, 1993; Holmes, 1998). These attitudes tended to become more repressive as the degree of intimacy increased (Owens, Griffiths, Feldman, Sales & Richards, 2000). Studies from the 1970s consistently found that around 80 per cent of parents of children with LD and their service workers favoured sterilization of people with LD as a preferred method of birth control (e.g. Alcorn, 1974; Whitcraft & Jones, 1974). Perhaps more surprisingly, however, when a more recent study of teachers re-examined the issue (Wolfe, 1997), it was found that 83 out of the 98 teachers and administrators thought that sterilisation should be encouraged for people with LD, regardless of the severity of disability. Seventy-six felt that people with LD should not be allowed to have children. In fact, it seems that the attitudes of teachers and professionals were more negative at the end of the twentieth century than twenty years previously (Griffiths & Lunskey, 2000).

It would be hoped that the attitudes of staff and professionals towards sexuality in people with LD might have altered in the decade following the publication of *Valuing People* (2001). Indeed, there is some evidence to suggest that opinions are beginning to alter in this area. In a study of 85

employed caregivers, Swango-Wilson (2008) found that although the majority of caregivers were unsure whether sexualised behaviour was appropriate for individuals with LD, there was a clear age distinction amongst caregivers: the younger caregivers were significantly more likely to display attitudes accepting of sexuality amongst people with LD than older caregivers.

Similarly, it was found that, in response to an anonymous questionnaire, staff caregivers working with people with LD were significantly more likely than family caregivers to accept the rights of people with LD to engage in sexual relationships (Evans, McGuire, Healy & Carley, 2009). This was cited by the authors as evidence that the attitudes of services providers were coming in line with ideological advances in relation to the rights of people with LD. However, on closer examination of the results, only 55 per cent (85) of staff felt that it would be acceptable for people with a mild LD to engage in an intimate sexual relationship, while only 48 per cent (74) of staff felt that a person with a mild LD should have the opportunity to get married. In the same study, staff were presented with a scenario in which a 25-year-old woman with LD fell pregnant with her boyfriend, and were asked to provide suggestions as to how they might proceed. While staff were more likely than family carers to offer supportive suggestions, only 19 per cent suggested that the girl would be able to raise the child with support. This is clearly at odds with the ideologies of normalisation and inclusion, and suggests that although attitudes may be changing, there remains a significant minority (or at times, a majority) of staff who remain resistant to the idea of people with LD as sexual beings and even more so, as parents.

There has been limited research, to date, investigating any differences between professional groups in their attitudes and opinions regarding people with LD as parents. One small-scale study (n=91) addressed the issue, investigating attitudes towards sexuality in people with LD amongst groups of special educators, social workers, nurses and physiotherapists (Parchomiuk, 2012). The only difference found was the comparatively higher level of acceptance displayed by social workers compared to special educators in terms of sexual intercourse between individuals with LD.

Although all groups displayed conservative attitudes towards the idea of people with LD as parents, there was no significant difference between the groups. In a similar study, Grieve, McClaren, Lindsay and Culling (2008) found no significant differences between attitudes towards sexuality and parenthood in people with LD between unqualified care staff and qualified nurses working with people with LD. However, they did demonstrate a significant positive correlation between the level of training amongst all staff and more liberal attitudes, which has clear implications for practice.

As an extension of research investigating the attitudes of staff working directly with people with LD, Gilmore and Chambers (2010) explored differences between 188 LD staff and 50 leisure workers, who tended to come into regular contact with people with LD. In general, no differences were found between the two groups in their attitudes towards sexuality in people with LD. However, one key significant difference emerged in the fact that professionals working with people with LD were significantly more conservative in their opinions about people with LD as parents, compared to the general public. LD staff cited several reasons for their conservative opinions, including the idea that people with LD would not be able to care for their children and that they would pass on genetic disabilities. These ideas clearly reflect the legacy of the myths regarding parents with LD.

### ***1.3 Discrimination against parents with LD***

The following section examines whether parents with LD face discrimination by professionals in the form of the decisions being made about whether or not their children should continue to live at home or should be removed. Authors writing in this area make one key caveat in their arguments: it is acknowledged that there will be cases in which children of parents with LD (as with any parents) are removed due to legitimate welfare issues, and these cases are not questioned (McConnell & Llewellyn, 2002). However, evidence suggests that the removal of children of parents with LD is frequently unnecessary, unwarranted and based on misguided assumptions about the parents rather than issues of child protection (Booth & Booth, 2004).

### *1.3.1 Outcomes of Child Protection proceedings for parents with LD*

Since interest in the area began some three decades ago, studies worldwide have consistently demonstrated that the rates at which children are removed from parents with LD are substantially higher than rates in the normal population. In a small study in Sweden, Gillberg and Geijer-Karlsson (1983) found that eighteen out of forty children (45 percent) of parents with LD were placed with foster families. A similar larger scale study in the USA demonstrated a similar figure, finding that, of 226 children born to parents with LD, 45.5 per cent of them had been removed (Accardo & Whitman, 1989). Similarly high rates of child removal were reported in Australasia, with a New Zealand study reporting a rate of 41 per cent from 96 children (Mirfin-Veitch, Bray, Williams, Clarkson & Belton, 1999), while research in Australia suggested a slightly lower rate of removal of around one third of 116 children (Bowden, 1994).

It is important to note that although these findings have been relatively consistent, they potentially represent a skewed sample, due to difficulties in sampling described above: research participants are frequently not only identified through, but also defined by their involvement with specialist LD services. Since parents often only become known to services at times of crisis, the samples are likely to encompass the subgroup of parents with LD most at risk of child protection issues, and might in fact ignore a group of parents with LD who are coping sufficiently without support and never become known to services.

A second kind of study investigating discrimination against parents with LD has examined the prevalence of this particular population amongst samples of families in court proceedings or child protection. In the first of its kind, Taylor et al. (1991) found in a US sample, that around 15 per cent of parents from a court sample of 206 cases had a learning disability. In Australia, a review of 285 care proceedings demonstrated that 8.8% of cases featured a parent with LD (Llewellyn, McConnell & Ferronato, 2003). Given a general population estimate for parents with LD of less than 1% (McConnell et al, 2000), this constitutes a clear over representation of these parents in child protection proceedings. They also noted that, compared to

parents with physical disabilities, mental illness or drug/ alcohol abuse, parents with LD were significantly more likely to receive an order to place the child out of the home or family.

In the most comprehensive study of the situation in the UK, Booth and Booth (2004) investigated all cases of care proceedings in Sheffield and Leeds in the year 2000. Of 437 care application, 66 involved at least one parent with LD. Additionally, 21 further cases involved a parent with borderline LD. In total, 15.3 per cent of all the children subject to proceedings came from a family headed by a parent with LD, a figure which increases to 22.1 per cent if borderline cases are included. Only 10% of the children were returned home, while three-quarters were placed in care outside of the wider family system, with over 40 per cent being freed for adoption. These figures are significantly higher than for parents in the same sample without LD. In fact, the percentage of the children of parents with LD freed for adoption was significantly higher than a comparison group of parents who had both mental health and substance misuse problems.

Interestingly, when findings from UK court proceedings are contrasted with comparable findings from Australian court outcomes, it was striking to note that parents with LD were substantially more represented in court proceedings in the UK than in the Australian sample (Booth, Booth & McConnell, 2005). Strikingly, of those cases involving parents with LD, UK children were much more likely to be placed outside of the family than Australian children (75% compared to 22%) and conversely, Australian children were more likely to remain with their parents than UK children (59% compared to 10%). It is important to note that due to the low numbers involved in these comparison groups, this difference might well be exaggerated, and might also reflect more systemic attitudes towards child placement in the respective countries. However, the authors hypothesise that social and cultural factors surrounding the label of LD might exert influence in such cross-cultural comparisons.

The lack of a well-defined control group in these examples makes firm conclusions about discriminatory practices problematic, without examining the more qualitative data from decision-making processes for these court

decisions, which will be discussed below. In one attempt to provide such a control group, however, an audit of social work cases carried out in a sample of UK local authorities, compared cases involving parents labelled with LD with a comparison group without a label (Cleaver & Nicholson, 2003). It was found that the labelled group were more likely to have had an initial assessment carried out, and were more likely to have had their children placed in the looked-after system.

One group of parents who might be expected to experience similar difficulties as parents with LD in the child protection system is parents with mental health issues. Indeed, it has understandably been demonstrated that this comparison group find court proceedings similarly distressing and overwhelming (Booth & Booth, 2005). However, in contrast to those with LD, where their disability is often the focus and cause of proceedings, those with mental health difficulties appear to face the opposite issue: little consideration is paid to the potential impact of parental mental health issues on a deteriorating home situation (Sheehan & Levine, 2005). Where the emphasis in social service involvement is on mental health issues, these parents face a similar focus on risk rather than strengths (Boursnell, 2012), yet their child placement outcomes remain significantly more favourable than parents with LD, despite clear evidence suggesting that parental mental illness can negatively affect child well-being (e.g. Giallo, Cooklin, Wade, D'Esposito & Nicholson, 2013). This difference might well reflect a sense that mental health issues are more likely to be temporary than LD, and parenting with mental health issues lacks the associated moral outrage that can accompany people with LD entering into parenthood.

### *1.3.2 Stigma in people with LD*

Stigma can be defined as comprising cognitive, emotional and behavioural aspects, which would relate to stereotypes, prejudice and discrimination respectively (Werner, Corrigan, Ditchman & Sokol, 2012). In this way of thinking about stigma, negative attitudes or stereotypes about a subgroup of people can lead to prejudice and discrimination against this group, because of the negative evaluation it produces (Corrigan, 2000). People with LD are amongst the most highly stigmatised groups in society



(Thomas, 2000), and this applies to parents with LD too, with some of the most common misconceptions about parents with LD having been described above. Recent research has demonstrated that individuals with LD are indeed aware of the stigma associated with their disability (Jahoda, Wilson, Stalker & Cairney, 2010) and that this experience is emotionally painful (Beart, Hardy & Buchan, 2005).

The concept of 'self-stigma' developed out of labelling theory (Scheff, 1966), which posits that when given a label, such as 'mentally ill' or 'learning disabled', expectations are placed on the individual which they eventually live up to, creating a self-fulfilling prophecy. The emerging 'why try?' model of self-stigmatization includes three elements: awareness, agreement and application (Corrigan, Larson & Rusch, 2009). In this model, therefore, a person must be aware of assumptions surrounding them (e.g. Parents with learning disabilities cannot cope), agree with that assessment (e.g. it is right that a parent with learning disabilities cannot cope) and lastly, apply it to themselves (e.g. I am a parent with learning disabilities and therefore I cannot cope). It is clear how such a cognitive process could produce an emotional response of decreased self-esteem and self-efficacy and a behavioural response of giving up (Markowitz, 2001). In fact, this idea of self-stigma is thought to lie along a continuum: while some internalise stigma, and act in accordance to stereotypes, others become almost empowered by stigma (Corrigan, Faber, Rashid, & Leary, 1999). Through an anger response to the indignation of being labelled, people at the empowerment end of the continuum can be energised to disprove stereotypes and feel corresponding confidence and self-efficacy. Factors which appear to explain the difference in how a person might react to stigma are the degree to which they agree with the initial assumption and the degree to which they identify with the labelled subgroup (Corrigan & Watson, 2002).

The idea of self-stigmatization in people with LD has only received limited attention, but where it has been investigated, a complicated relationship was found between awareness of stigma and the degree to which this was internalised (Jahoda et al, 1989; Finlay & Lyons, 1998). Both studies found that some participants felt fundamentally different from others without LD,

while some felt fundamentally the same. However, this latter group was divided between those who rejected the stigma associated with the label, and those who did not show awareness of stigma surrounding the label. Where lack of awareness was the issue, several hypotheses have been put forward, including cognitive development, denial and a differentiation between awareness at the level of discourse and experience (Beart, Hardy & Buchan, 2005). In terms of cognitive development, for instance, Cunningham, Glenn and Fitzpatrick (2000) found that of 77 young people with Down's Syndrome, 41% showed no awareness of their own learning disabilities or any stigma surrounding it. Sinason (1992) has argued that lack of awareness serves a more protective function, in defending against the pain of stigmatization. Finally, it is hypothesized that people with LD might understand the experience of stigmatization, but not have the linguistic skills to engage in discourse surrounding it (Davies & Jenkins, 1997). In qualitative research with parents with LD regarding their experience of stigma, therefore, it may be important to consider all of these hypotheses.

For parents with LD, the experience of stigma might have a more specific consequence. It has been hypothesised that, in order to avoid the distress associated with such stigma, parents may assume a 'cloak of competence' (Edgerton & Bercovici, 1976), in which they adopt strategies that make them appear more able than they are. When this leads parents to refuse help, it may in fact serve to reinforce the stereotype, as they may be seen as un-cooperative and unable to change by those who are predisposed to focus on the negative (Aunos & Feldman, 2002).

### *1.3.3 Theory of planned behaviour*

It has often been assumed that the attitudes a person holds will be directly predictive of their resulting behaviour. However, decades of research have demonstrated that the relationship between the two is far from straightforward, with a number of other factors implicated in attitude-behaviour consistency (Glasman & Albarracín, 2006). One model for understanding the impact of professional helping behaviour, and the extent to which it is based on attitudes, is Azjen's (1991) Theory of Planned

Behaviour. This is a well-researched model that accounts for a considerable degree of variance in intention to perform support-related behaviour (Martin, McKenzie, Newman, Bowden & Morris, 2011). According to the theory, intention to perform a behaviour is related to three key factors: Firstly, attitudes towards the behaviour, which includes both a positive or negative evaluation of the behaviour, as well as a belief about the behavioural outcome; Secondly, the influence of normative beliefs, or the extent to which it is believed that the behaviour matches social norms; and finally, beliefs about ability to perform the intended behaviour, which can include having necessary skills and sufficient time and resources.

For professionals, therefore, if the intended behaviour was to provide competence-enhancing support for parents with LD, the theory can explain professional variability in supportive behaviour. Thus, professional behaviour would be influenced by fundamental attitudes towards parents with LD, whether professionals believe supporting parents will lead to a satisfactory outcome, whether supporting parents with LD fits with the perception of prevailing orthodoxy, and the extent to which professionals feel well-equipped to provide such support. It can therefore be seen that where professionals hold negative assumptions about parents with LD being capable, especially if they are provided with inadequate resources, it is possible that they will not behave in a manner which is supportive of parents.

Although there has been no published research to date investigating this idea in the area of staff supporting people with LD, an unpublished DClinPsy Thesis researched the phenomena. Gallagher (2011) investigated the attitudes of professionals supporting people with LD with regard to sexuality and found that liberalness of attitude was predictive of the intended behaviour to support these individuals with behaviour related to sexuality.

#### *1.3.4 Treatment of parents with LD by professionals*

Given that stereotypical attitudes appear to linger in professional minds, it is important to consider if and how this might be manifested in the treatment to which parents with LD are subject. As described above, parents with LD are significantly over-represented in child protection

proceedings and are more likely to have their children taken away from them, however, this is not sufficient evidence to say they are being unfairly discriminated against. However, numerous case-by-case reviews of court proceedings against parents with LD have found evidence of custody decisions being determined by stereotypical myths, such as the inevitability of parental inadequacy and an inability to learn (e.g. Hayman, 1990; Marafino, 1990; Levesque, 1996).

In the more recent past, Booth and Booth (2004) found that, of 63 cases of children removed, one third cited LD as a specific reason for removal, and in particular, that parental LD would make any change or improvement in their circumstances impossible. This was echoed in an Australian sample (Booth, Booth & McConnell, 2004), in which court reports are littered with evidence of assumptions about parents with LD, with decisions being made using the diagnosis of LD as a causative factor in close to half the examined cases. Judgements included such phrases as "There is nothing one can do to improve an individual's intelligence in order to acquire a better level of parenting ability" (p. 22) and "The mother has learning difficulties which make it impossible for her to function adequately as an independent adult" (p. 23).

In addition, in the UK sample, of the cases where children were removed from their parents, close to 20% were done so against the explicit advice of an independent professional (often a psychologist), who had reported that the parent was capable of providing adequate care with the right support; in the majority of cases, the child was removed in the anticipation of potential risk, rather than due to any direct evidence of abuse or intentional neglect.

McConnell, Llewellyn and Ferronato (2000) presented evidence in which child protection workers cited a presumed causal link between child developmental delay and parental IQ as a reason to remove children. This was true even in cases where developmental delay was not evident, as there was a presumption that this outcome was inevitable given sufficient time.

It is not only in the decisions made by courts in which the action of professionals is crucial in the potential success of a parent with LD. The kind

of support received by parents is just as important, as it can serve to empower or undermine parents, as recognised by Feldman's (2002) interactional model. In one of the only papers of its kind, Tucker and Johnson (1989) highlight the difference in support provided for mothers with LD which is competency inhibiting and competency enhancing. Using a combination of observation and interview with twelve families, they found that those service providers who provided competency promoting support assumed that the parent could eventually learn the necessary skills and were committed to teaching. They were keen to provide the parents' skills that would enable them to make decisions alone, and when crises occurred, they were able to intervene in a way which did not elicit feelings of utter incompetence. On the other hand, competency inhibiting support was based on the assumption that the parent would never be capable of parenting their child independently. The task of providing support was therefore seen as burdensome and ultimately pointless. The parents were given little chance to make decisions independently, and support providers tended to step in long before a crisis, leaving the parent feeling incapable.

The concept of empowerment in parenting, originally described by Dunst, Trivette and Deal (1988) became an important driving force behind how services planned and delivered early interventions with parents. In 1990, Espe-Sherwindt and Kerlin called for the concept of empowerment to be applied as much to parents with LD as for the general population of parents. This potential direction of research has mostly been ignored by authors interested in parental LD. However, they stressed the importance, and indeed successful impact, of a programme of support for parents with LD which is based on the assumption that parents will be able to learn and be successful parents. Where professionals were able to act based on these principles, families demonstrated higher self-esteem, greater self-efficacy and greater satisfaction with services.

Deeley (2002) offers a useful perspective on the individual differences seen amongst professionals working with parents with LD in terms of their helping behaviour. She notes an ideological difference between professionals in terms of whether they are a 'normalisers' or 'paternalists'. In this context, 'normalisers' adhere to the principles that people with LD

have the 'freedom to live a life based on the same values and on the same terms as others in society' (Perrin & Nirje, 1985). Professionals with this view acted in a way which promoted choice and autonomy and perceived people with LD to have hidden potential which needed to be developed. On the other hand, 'paternalists' viewed people with LD as eternal children, who needed to be cared for and who were not capable of raising children. Interestingly, the dividing line between 'normalisers' and 'paternalists' was their length of service, in that those staff newest to the service subscribed to the newer ideology of normalisation, while longer-serving professionals remained faithful to the superceded orthodoxy.

If some professionals do indeed hold negative stereotypes about parents with LD, as appears to be the case, it is important to consider how the way they process information might be affected in their interactions with and decisions about parents. At the most basic level, if a person encounters and labels someone as belonging to a group about which they hold negative stereotypes, they are likely to respond less positively and less quickly than to an ingroup member (Fiske, 1998). For someone using stereotypes, once they have placed a person into a stereotyped group, they tend to 'stereotype-match' behaviour, in that they will neglect neutral or ambiguous information, but assimilate any negative information to confirm their initial assumptions (Krueger & Clement, 1994). In fact, they may actively search for information that confirms their assumptions, by asking questions which are likely to result in stereotype-matching responses (Leyens, Yzerbyt & Schadron, 1994).

If parents with LD are perceived to be an outgroup by professionals (i.e. a group with which the perceiver would not identify) then some professionals may be prone to consider the outgroup to be a particularly homogeneous entity (Brewer & Brown, 1998). This could lead to parents with LD all being judged the same way, and information gathered about one parent with LD being used to inform assumptions about another. Finally, underlying stereotypes can cognitively predispose a person to make stereotypic attributions about a person's behaviour: for parents with LD, this would mean that a professional, working on assumptions, would attribute stereotype-congruent behaviour (e.g. lacking knowledge) to their status as

a learning disabled parent, but would attribute behaviour which did not match the stereotype (e.g. performing well) to temporary circumstances (Fiske, 2000).

## **1.4 Assessing parents with LD**

### *1.4.1 Factors influencing parenting adequacy in people with LD*

Parenting is often seen as the task of facilitating a child's development in a safe environment (Reder, Duncan & Lucey, 2003). However, definitions of 'good parenting' vary in their conceptualisation, with research considering ideas of 'competent parenting', 'parenting capacity' and 'good enough parenting'. Statutory services in the UK rely on assessment of parenting capacity when considering children's needs, which includes domains such as: ensuring safety, emotional warmth, stimulation, guidance and boundaries, basic care and stability (DoH, 2000). Despite this skills-based focus, it has been shown that social workers' primary focus when considering parenting is the prevention of harm (Woodcock, 2003) and there remains considerable variability amongst practitioners in their conceptualisation of what constitutes 'good enough' parenting (Newman, Day & Warden, 2005).

Without a clear and consistent definition of adequate parenting, decisions about a parent with LD's fitness to parent becomes a subjective process, based on value judgements (Sheerin, 1998). There exists little clear-cut evidence pointing to what distinguishes a successful parent with one whose parenting is deemed inadequate. Even so, the desire remains to systematically predict risk for parents with LD, by investigating what factors separate 'high-risk' from 'low-risk' parents (McGaw, Scully & Pritchard, 2010). Research into parental adequacy has tended to focus on three kinds of outcome measure: a direct assessment of some measure of parenting (e.g. parenting style); the presence or absence of abuse or neglect; or in terms of child characteristics (e.g. child behaviour).

While models of determinants of parenting have been extensively researched in the general population (e.g. Belsky, 1984), there is no evidence to suggest that such a model could be directly generalised to parents with LD. In fact, given the specific challenges faced by such a

population, it is likely that the model would need to be adapted to incorporate their unique experiences. As cited in the journal article above, an effort was made to address this by Feldman (2002). In a comprehensive integrative model, Feldman proposes that several areas can impact on parenting success, largely mediated by their impact on parental health in the form of illness, depression, stress and low self-esteem. These factors include: social factors, comprising stigma and discrimination; the mother's developmental history, including her level of cognitive ability, history of abuse and poor parental role models; social support and services, which includes the nature of service provision; socio-economic status, which considers low income, poor housing conditions and dangerous neighbourhoods; life crises, such as current abuse and victimisation; and child characteristics. Aunos and Feldman (2002) expand on one aspect of this model: the relationship between discrimination, social support and parenting outcome. They hypothesise that the stigmatization parents with LD experience adversely affects their mental and physical health, and thus their parenting ability. However, they also propose that the experience of discrimination causes parents to assume a 'cloak of competence' (Edgerton & Bercovici, 1976) in which they refuse offers of support in order to appear more able than they are. Without the appropriate support, parents are less able to parent effectively.

Many of the specific challenges parents with LD face are in relation to the factors presented in Feldman's model: Mothers with LD are shown to experience greater stress than mothers without LD (Feldman, Leger & Walton-Allen, 1997); they are more frequently living in poverty (Booth & Booth, 1994) and more likely to experience co-morbid mental health problems than the general population (Cooper, Smiley, Morrison, Williamson & Allen, 2007). Perhaps most importantly, parents with LD are often socially isolated (Myers, Ager, Kerr & Myles, 1998), even though they report a higher perceived need for social support (Feldman, Varghese, Ramsay & Rajska, 2002).

Despite these challenges, the evidence supporting Feldman's model of parenting is relatively limited. Early evidence which offered some support was methodologically flawed, based on small sample sizes, and often using



parents with borderline LD (IQ of up to 85) and generalising to an LD population (Dowdney & Skuse, 1993). With regard to parental IQ, recent studies have found no significant difference in the IQ of parents with LD whose children were placed on Child Protection compared to those who were not (McGaw, Scully & Pritchard, 2010) and no relationship between maternal IQ and child developmental outcomes in mothers with LD (McConnell, Llewellyn, Mayes, Russo & Honey, 2003). It appears parental history of trauma plays more of a role in parenting success, as parents with LD whose children are in Child Protection are significantly more likely to have experienced childhood trauma than those parents whose children were not in Child Protection (McGaw, Shaw & Beckley, 2007)

Given the central role attributed to parental mental health and stress in Feldman's model, the evidence is surprisingly mixed. While some studies show no link between parental mental health and outcomes of parental adequacy (Aunos et al., 2008), others have demonstrated a link between parental mental health and the likelihood that a child would be in Child Protection (McGaw et al., 2007). However, when the role of increased stress alone was examined, it was found to be positively correlated with child problem behaviours and negatively correlated with positive parenting style (Aunos et al., 2008).

In terms of partner and child characteristics, the partner of a mother with LD was found to represent an increased risk to the outcome of child protection proceedings when the partner's IQ was discrepantly higher than the mother's (McGaw et al., 2010). There has been limited research to date investigating the impact of child characteristics on parenting success. Social support and services received are also shown to have a mixed role in parenting outcomes. It appears that it is a parent with LD's satisfaction with social support and service provision that is more influential than size or source of support (Feldman et al., 2002).

What appears clear, is that further exploration is required to lend support or suggest adaptations to Feldman's model. The influence of negative attitudes and discrimination, for instance, although intuitive, has not been investigated to date in this population. It also emphasises the complexity of

issues surrounding a person with LD's potential to succeed as a parent and the limitation of an approach which views IQ alone as predictive of parenting adequacy.

#### *1.4.2 Assessment practice for parents with LD*

As detailed above, parents with LD are over-represented in the courts, and there are multiple, complex, potentially interacting risk and protective factors which are important in determining parenting success. Given these facts, and the potentially prejudicial assumptions of incompetence from professionals involved (Goodinge, 2000), a clear, structured and transparent assessment of parental ability in parents with LD, which maximises objectivity and minimises potential for bias is of paramount importance to assist professionals in their decision-making process (McGaw et al., 2010). There is, in fact, comprehensive national guidance available in the UK to guide professionals through the assessment process.

The 'Framework for Assessment of Children in Need' (DoH, 2000) is intended as guidance for the assessment of any parent, including parents with LD, and is based on a model of strengths and risks (Sellars, 2011). It guides practitioners to assess for strengths and risks in three areas: child developmental needs; the capacity of the parents to respond to the child's needs; and the role of wider family and environmental factors. Cleaver and Walker (2004), in an extensive audit of staff and families, found that where the guidance had been adopted, it had enhanced parents with LD's understanding of the assessment process and their involvement at all stages of assessment.

Despite the available guidance, current practice in parenting assessments for people with LD are described as inconsistent, unstandardized and often not sufficient for purpose (DoH, 2007). One potential reason for this is the lack of available assessment tools designed for the specific population, combined with undertraining of staff in their use (Tarleton et al., 2006). In fact, assessments continue to rely on subjective opinions of professionals, and tend to focus almost exclusively on negative aspects of parenting, steering the assessor to an inspection of risk (Newman, 2004).

In the current climate, following several high profile cases involving the death of children known to social services, child protection workers are increasingly risk averse (Munro, 2010). There is no reason to suspect that this culture of risk aversity is not transferred to parents with LD as well. When assessments focus, as they tend to do, on risk factors rather than parental strength and resilience, results are not likely to paint an optimistic picture (McGaw & Sturmey, 2006).

Booth and Booth (2005) offer five key aspects of a good assessment for parents with learning disabilities: it should take place at the parent's home; psychometric assessments should not provide a sole measure of parenting capacity; the assessment criteria and expectations of the parents should be made explicit; parents should be provided with independent support to help protect their views and interests; assessments should involve people experienced in working with individuals with LD. They noted that of 25 parents with LD interviewed about this topic, very few had experienced any of these points of good practice during their assessments.

In spite of the characterisation of assessments as inefficient and open to bias, there has been no research published to date which examines the perception of assumptions during the assessment process from the point of view of the parent. The current study will aim to address this issue.

#### *1.4.3 Regional variability in service provision*

It is acknowledge that there remains considerable regional variation in the overall level of service provision for people with learning disabilities by health and social services (Emerson, Hatton, Robertson, Roberts, Baines & Glover, 2010). The situation is continuing to change as individual departments are forced to streamline their core services to meet recent budget constraints.

This variability was also seen in the most recent review of services for parents with learning disabilities (Tarleton, 2006), which noted pockets of good practice dispersed amongst general low levels of available support. While some counties maintain comprehensive parenting services for people with LD (e.g. Cornwall's Special Parenting Service), the three counties

investigated in the current study provided variable levels of support within their general service. Until recently, Nottingham's CLDTs had maintained an emphasis on working with parents with LD, using established links with local Sure Start centres to identify and provide support for these parents. Funding for this initiative was withdrawn and the teams were working with very few parents with LD at the time of recruitment. The CLDT in Lincolnshire had historically not assessed or worked with parents with LD. Due to resource limitations, their criteria for accepting referrals to the service focusses on those with moderate or severe LD, which tends to preclude parents with LD. Finally, Norfolk CLDTs continue to work with a relatively large number of parents with LD and are highlighted in Tarleton's (2006) report as offering specialist parenting courses and employing a specific co-ordinator for parents with LD.

### ***1.5 Parents' views of services***

The concept of using qualitative research methods with parents with LD is a relatively new one, largely due to reservations about the ability of people with cognitive impairments to participate in research which places such focus on verbal abilities. However, with the rise of the inclusion movement, it has been increasingly recognised that people with LD represent important collaborators in research (Nind, 2008). Two authors in particular have been responsible for driving the interest in interviewing people with LD (e.g. Booth & Booth, 1997; Booth & Booth, 1998; Booth & Booth, 2006). However, in these cases, the authors favoured an approach by Terkel (1968), which 'eschews methods' and rules, instead simply presenting the story of uncelebrated individuals without interpretation or commentary. Other research has relied on extremely small numbers of case studies of people with LD (e.g. Jahoda, Wilson, Stalker & Cairney, 2010).

For parents with LD, opinions on support provided has tended to come from the support providers rather than the parents themselves (Newton et al., 1994). In a preliminary attempt to address this issue, Guinea (2001) interviewed eight parents with LD, and found that the majority considered one or more professionals to be key people in their lives, although five parents desired more emotional and practical support from their key

worker. In a more extensive study, parents admitted their unwillingness to engage with services around the care of their children (Tarleton et al, 2006). They felt ignored, unsupported and singled out for harsh treatment by services. Similarly, in Booth and Booth (2004), parents expressed their dissatisfaction with the way court proceedings were carried out: they felt confused during meetings, overwhelmed by the numbers of professionals involved and lonely and unsupported during case conferences. Parents were just as able to describe, through qualitative research, what they find helpful from therapeutic interventions, highlighting the importance of long-term support, delivered by respectful and straightforward professionals who are willing to listen to parents' concerns (Ehlers Flint, 2002).

## **2. EXTENDED METHOD**

### *2.1 Thematic Analysis*

Thematic analysis has tended to be described as a poorly demarcated set of methods, which might not constitute a qualitative research method in its own right (e.g. Ryan & Bernard, 2000). However, more recently, researchers have sought to provide more definition and clarity about thematic analysis, in order that the choices behind the analysis might be made more explicit (e.g. Braun & Clarke, 2006). Thematic analysis is not bound to one epistemological stance, and can sit comfortably in essentialist or constructionist frameworks, and in this case, the research is grounded in a critical realist method.

Thematic analysis was chosen in these circumstances for several key reasons. Firstly, Braun and Clarke (2006) noted that thematic analysis can provide a useful way to analyse a comprehensive data set when a specific area has yet to be studied in depth, which is certainly the case for the current research. Secondly, thematic analysis allows for a more flexible approach to data analysis which can be either inductive, where themes are tied closely to the data (Boyzatis, 1998), or deductive, in which themes are more theory-driven and which might use codes developed a-priori from relevant literature (Crabtree & Miller, 1999). This was a strength for the current study, which employed a more integrated method of inductive and

deductive approaches, the use of which has been outlined by Fereday and Muir-Cochrane (2006). This allowed the research to address specific research questions based around the known assumptions about parents with LD, while providing space to capture the experience of a group of individuals who have had little chance to tell their stories. Finally, thematic analysis allows for the saliency of data extracts to be taken into account, rather than simply their frequency as might be the case in content analysis, for instance. Although content analysis might have allowed for greater generalizability of findings, it would have been too reductionist for the current research, ignoring importance in favour of recurrence (Buetow, 2010).

There is little in the way of evidence-based recommendations for effective sample sizes for thematic analysis (Baum, 2002). Recent thematic analyses undertaken with people with LD in the target journal for the current research have used samples ranging between nine (Carlson, Armitstead, Rodger & Liddle, 2010) and thirteen (Kilcommons, Withers & Moreno-Lopez, 2012). A key idea in qualitative research is the idea of data saturation, which proposes that sampling should continue until no new codes are found in the data (Patton, 2002). This is obviously dependent on the initial stages of data analysis occurring concurrently with data collection. However, given this criteria alone, it becomes difficult to estimate prior to the start of research, how many participants might need to be recruited. A recent study, however, examined the course of saturation over the thematic analysis of sixty interviews (Guest, Bunce & Johnson, 2006). It was found in fact that 73% of codes had been established within the first six transcripts, while the range of thematic discovery was almost complete after the following six (92%). They also demonstrated that in terms of overall prevalence of the codes, good internal reliability (Cronbach's  $\alpha > .70$ ) was established after the second round of analysis, in other words after twelve transcripts. Other authors note that there are obvious pragmatic considerations to establishing sample size (Tuckett, 2004). Since the current study is investigating a relatively homogeneous sample, using a more structured interview schedule and due to the small total population size, a target of 10-15 participants was chosen. Data saturation was

checked by establishing codes after each interview was conducted. Few additional codes were found following the eighth and ninth interviews, while the final interview offered no new codes.

An alternative methodology which was considered for the current study was Interpretive Phenomenological Analysis (IPA). This is a similar approach, which can use semi-structured interviews in an attempt to understand an individual's experience and how they make meaning of that experience (Smith, 2004). One difference that added weight to the choice of thematic analysis is that in its purest form, IPA would use an interview structure with minimal prompts, and an open invitation for participants to 'tell their story' (Smith & Osborn, 2003). This is at odds to the style of qualitative research necessary to facilitate engagement with people with LD, where closed questions, prompts and probes may need to be available.

## *2.2 Inclusion Criteria*

As stated above, the inclusion criteria for the current study were very specific. The key decision was to involve only parents whose children remained living with them at home. Although this made recruitment substantially more difficult, the reasons for this were two-fold: firstly, it allowed parents to consider in what way their interactions with professionals impacted on their current parenting ability; secondly, it established the fact that these parents were deemed capable of raising a child safely, even if their ability was questioned substantially along the way.

Parents were only included if they currently accessed specialist services for people with LD, which was reflective of the social definition of learning disability applied to the research, but also ensured that a potentially vulnerable population had immediate access to professional support if necessary following the interview and that any concerns raised regarding safeguarding could be passed on to a familiar professional.

## *2.3 Participant Synopses*

All names have been replaced with pseudonyms to ensure participants are not identifiable.

### Joyce

Joyce is a 41 year old woman from Lincolnshire, who lives with her husband, Steve, along with her mother and her 16-year-old son, Luke. Her daughter, Josie, was removed by social services as a toddler after she contracted meningitis. Joyce has quite severe epilepsy which she struggles to manage on a daily basis. Her partner Steve, who she has been with for eighteen years, does not have a learning disability and works full-time to support their family. Her son, Luke, has no physical or mental health problems and is getting on well at school, which is a source of great pride for Joyce.

### Larry

Larry lives together with Laura, and his son Connor. Connor has no physical or developmental difficulties, and services have no concerns at present about Larry & Laura's parenting ability. Larry is described as having a mild learning disability and is provided support each week to assist with practical tasks, such as budgeting. No results from cognitive assessments were available for Larry.

### Laura

Laura is 30-year-old woman, who lives with her partner, Larry, and her 2-year-old son, Connor. Norfolk learning disability services have been involved with Laura and her family since Connor's birth, and undertook an in depth assessment of her parenting skills to see what level of support would be necessary. Laura experiences quite severe social anxiety, and found the process of the interview difficult to cope with, although she was determined to tell her story.

### Greg

Greg is a 38-year-old single father from Norfolk, with a teenage son, Paul. Paul's mother left the family when he was three years old, and this seems to have been a positive outcome for Greg and his family. Paul's mental health difficulties became increasingly difficult for Greg to manage as he got



older, and recently, Paul has begun to spend time at a residential facility, although Greg maintains full parental responsibility.

### Esther

Esther is a 45-year-old lady with learning disabilities, who lives with her husband, Alan, and her son, Samuel. Esther suffers with Cerebral Palsy, which affects her ability to do some physical tasks, and makes it difficult for her to work. Esther and her family have quite a lot of involvement with services in Nottinghamshire, due to her son's extensive physical and intellectual disabilities. Although she attended special school, Esther was only identified as having a learning disability for the purposes of accessing adult LD services after her son was put on a Child Protection Order, due to his difficulties swallowing.

### Fiona

Fiona is a 36-year-old woman, who lives at home with her two children, aged 16 and 12. She lives with a long-term partner, who is not the children's father, who plays a large role in caring for Fiona and her children. Her partner is not always seen as positive influence for Fiona. Her older daughter has substantial learning disabilities, while her son is described as being 'bright as a button'. Fiona has regular contact from the recovery team in Lincolnshire, as she struggles with mental health difficulties, which have led to her being institutionalised in the past.

### Alan

Similarly to his partner, Esther, Alan (45 years old) had never accessed LD services prior to a crisis with his son's health, in which their ability to care for his complex needs was questioned. Although Alan's IQ scores confirm he has a mild learning disability, he does not personally identify with this group, focussing instead on his dyslexia.

### Tommy

Tommy is a 51-year old man with three children, living in Norfolk, although only one child lives at home at present. Tommy has been married to Danielle for many years, although he could not remember exactly how

many! Social services only became involved in Tommy's life when he asked for help with his oldest son, who was falling in with the wrong crowd. This is a call which Tommy deeply regrets making, as the result was the removal of his daughter from their care.

#### Danielle

Danielle is a 45-year-old woman who has been married to Tommy for many years. As with Tommy, the arrival of social services in their life at a late stage has brought heartbreak for Danielle, when her daughter, Leanne, was placed into foster care. Although this was done on a voluntary basis, it didn't feel like a choice for Danielle, who is determined to learn and change whatever she needs to, in order to have her daughter home.

#### Georgia

Georgia is a 33-year-old lady with mild learning disabilities, who lives at home with three sons in Norfolk. Social services only became involved with Georgia and her family when her son made accusations of physical abuse at school. After investigation, this turned out to be a reference to the fact that Georgina and her partner sometimes smacked her son on the back of the hand when he was being naughty, and she was happy to work with services to learn alternative methods of discipline for her oldest son.

### *2.4 Qualitative methods with people with LD*

The use of qualitative methods with people with LD is a new field, with studies using interviews to seek the views of this diverse population still rare (Gilbert, 2004). This is as much due to past assumptions about the value placed on the opinions of this group, as the current difficulties in adapting research to facilitate the involvement of people with potential communication difficulties (Nind, 2008). However, it is increasingly recognised that with appropriate adaptations, people with LD can provide valuable insight through the standard semi-structured interview format which is so often employed in qualitative research.

Booth and Booth (1996) noted four key challenges that needed to be addressed when conducting research in this way: firstly, inarticulateness,

which combines both restricted language skills with low self-esteem and compliance; secondly unresponsiveness, in that people with LD may struggle to answer open-ended questions; next is a very concrete frame of reference, suggesting that people with LD might find it difficult to think in abstract terms; and finally, problems with time, in that it may prove difficult to orientate interviewees to past events.

These challenges were met in a number of ways in the current research. Firstly, a kind of funnelling approach to questioning was used: initial questions were open-ended, before becoming gradually more focussed and direct depending on the ability of the participant. If even focussed questions were out of reach, and providing the participant was not prone to acquiescence, prompts were used to offer and eliminate alternatives. Additionally, where difficult questions were met initially with confusion, they were progressively adapted to find a way of asking which fitted the participant's frame of reference. In order to meet the challenge of a concrete frame of reference, abstract questions were avoided where possible. However, since the research is investigating what other people may or may not think about them, a strategy was developed where concrete examples were directed to a more abstract position through serial questioning. For some particularly anxious participants, a family member remained present in the room throughout the interview, to support the participant and offer corroboration about particular facts which were of concern to the parent. Although this variation of approach between different participants in the same study is unusual for qualitative research, it was necessary and precedented (Gilbert, 2004) given the variability in linguistic ability of the samples.

## *2.5 Ethical considerations*

During the process of gaining ethical approval, three main issues were addressed: capacity to consent, sensitivity of research subject and confidentiality. The issue of capacity was of particular importance due to the inclusion of people with LD as participants.

The need to obtain informed consent from individuals to participate in research is as much a moral obligation as a legal requirement (Scott,

Wishart & Bowyer, 2006). The key component of informed consent for people with LD is their competence to make this decision on their own behalf. Traditionally, it has been assumed that people with LD would not have capacity, but this changed with the Mental Capacity Act (2005) in which competence is assumed unless assessment proves otherwise. Capacity to provide informed consent would comprise three elements: capacity to make a decision which weighs up potential consequences; having sufficient information available to make such a decision; and the ability to make the decision without coercion (Dunn, Nowrangi, Palmer, Jeste & Saks, 2006).

In order to address these issues, all information was presented for participants in an adapted, simplified form, which separated key points and was available in audio format as well as written. All participants were presented with the information initially by one of their care team, and had someone well known to them present at the consent meeting with the researcher to ensure no coercion was taking place. Finally, the researcher asked a series of questions relating to key points of the research and the potential advantages or disadvantages of taking part. The responses to these questions, alongside the opinion of a clinician who knew the parents well, were used to assess whether or not the participant had capacity to consent.

A particular part of this informed consent was making clear the professional boundaries of the research. People with LD tend to have small social networks, which are actually made up more of professionals than friends (Pockney, 2006). It has been argued that when researchers invite themselves into the homes of people with LD, the boundaries of relationships can be easily misconstrued (Stalker, 1998). It was therefore important to establish quick rapport while emphasising the temporary nature of the relationship, as well as the lack of ability of the researcher to make any changes to their support from services.

The second ethical area to consider was whether the sensitivity of the subject area of the research had the potential to cause distress. Although all parents maintained custody of at least one of their children, some had had

children removed by services. In order to mitigate potential distress as much as possible, parents were informed of potential interview topics prior to the discussion commencing and were made aware of the choice not to answer any questions and choose how much they wished to disclose. Additionally, the researcher was able to manage and support the participants through any distressing emotions during the interview, drawing on therapeutic skills as a Trainee Clinical Psychologist. Finally, all participants were able to contact a member of their care team following their interview if any further support was necessary.

The final key ethical consideration was of confidentiality and preserving the anonymity of participants. This was managed throughout the research process: consent forms containing identifiable data were stored separately to research data in a secure environment at the University of Lincoln; audio-recordings were stored on an encrypted memory stick and destroyed at the earliest opportunity; interviews were transcribed only by the researcher and were immediately anonymised by using pseudonyms for participants and their families; any other identifiable information (place-names, names of professionals, locations etc.) were either removed from the transcripts or disguised. Within this research, there was the possibility that disclosure could be made which indicated that a child or vulnerable adult was at risk. In this case, a member of the participants' care team would have been informed. Participants were made aware of this prior to participation.

## *2.6 Epistemology – critical realism*

As outlined above, this research is rooted in a critical realist epistemology, stemming from the ontological perspective that there exists a reality outside of what is observable, which consists of three domains (Bhaskar, 1998): the empirical domain, which includes all that is observable in our immediate experience; the actual domain, which refers to all that transpires, regardless of whether or not it is observed; and the real domain, which comprises all that exists, including the mechanisms by which events and other surface phenomena occur (Sayer, 2000). The task of research is therefore to 'investigate and identify relationships and non-relationships,

respectively, between what we experience, what actually happens, and the underlying mechanisms that produce the events in the world' (Danermark, Ekstrom, Jakobsen & Karlsson, 2002, p.21). A thematic analysis undertaken in this manner, would therefore be seeking to examine the lived-experience of parents with LD, exploring how they relate their empirical experience with events outside of their observation, as well as the generative mechanisms which might underlie these actions and events.

While qualitative research from critical realist position might investigate phenomena from a reported rather than a directly observable standpoint, this is not necessarily a disadvantage. Madill, Jordan and Shirley (2000), for instance, note that any account, whether from the participant or the researcher, is subjective and therefore not invalidated by contradictory perspectives. For instance, in the current study, it is possible that parents' ideas of professionals will offer a conflicting account to that which would be put forward by professionals. Similarly, a critical realist perspective would acknowledge that any perception of events is influenced by our beliefs and history (Bunge, 1993) and that any constructed knowledge is fundamentally subjective. Thus, the aim of the current research is not to provide an objective account of parents' experiences, but rather a contextual account of their perspectives.

Finally, critical realism offers a useful perspective on transferability of findings, based on broader notions of consensus and coherence theories of truth (Bisman, 2010). An observation is valid and useful when there is general group agreement and when it is compatible within a system or theory (Lincoln & Guba, 1985). Research questions can therefore be answered by searching for commonalities in data which fit coherently with underlying theory. This perspective fits clearly with thematic analysis and the intended aims of this project.

### *2.7 Reliability and Validity in Qualitative Research*

With the departure from the positivist tradition, the application of reliability and validity to qualitative research is a difficult task. While in quantitative research, such terms would reflect a desire for replicability of findings and whether the research accurately measures reality, in qualitative research,

they have been adapted to represent a drive towards credibility, authenticity, criticality and integrity (Whittemore, Chase & Mandle, 2001). One frequently cited method of assessing quality of qualitative research is by meeting four key criteria: sensitivity to context; commitment and rigor; transparency and coherence; and impact and importance (Yardley, 2000).

The first of these, sensitivity to context, includes awareness of relevant theories and literature, as well as attention to participant's situations and perspectives, and ethical issues. In the current study, such sensitivity has been demonstrated by the focus on relationship between interviewer and participant and the development of an interview schedule which is sensitive to the particular ability of the intended participants. These sensitivities might also be said to show commitment on the part of the researcher, combined with her prolonged engagement with the topic area over many years. The key concept of rigor can depend both on the adequacy of the sample and the completeness of interpretation. Efforts were made in the current study to ensure that the sample was sufficient to ensure saturation of the data, while representing as homogenous a sample as possible. The research also strived for transparency and coherence by ensuring that all themes from the data were presented in a convincing manner, reinforced by appropriate quotes taken from the data. Additionally, a reflective diary was kept throughout by the principal researcher, commenting on her thoughts, emotions and reactions to the interviews, thus allowing her to consider the impact of these on the final analysis. An audit trail was also compiled, which permits the key decisions and process of revisions to be scrutinized. The final criterion of impact and importance assesses the impact of the findings in socio-cultural and practical terms and will be considered in the discussion.

An alternative framework for assessing the quality of the current study would have been Braun and Clarke's (2006) criteria for conducting thematic analysis. Although this offers a useful, if rigid, checklist for the process of conducting such research, it offers little in the way of consideration of wider issues of quality in qualitative research. The difficulty of this pluralistic approach, in which each qualitative methodology creates its own standards

specific only to one author's approach to one method, is that it becomes problematic to assess and maintain standards across disciplines (Dixon-Woods, Shaw, Agarwal & Smith, 2004). Yardley's criteria avoid this issue by offering a universal standard against which any qualitative methodology could be measured.

### **3. EXTENDED RESULTS**

#### *3.1 Overview of extended results*

Results presented in the main article related to four super-ordinate themes. In the first, parents attributed four key assumptions to professionals: that parents would be unable to cope with children; that their children would also have LD; that parents would be unable to learn new skills; and that their children would therefore need to be removed. In the second super-ordinate theme and with these assumptions in mind, parents perceived that they were treated differently to other parents, at best in a paternalistic fashion, and at worst deliberately obstructed through unrealistic demands and/or accusations of guilt. The impact of this treatment (Super-ordinate theme 3), and the assumptions parents perceived it to be based on, had a clear emotional impact on parents, as well as on their relationship with services. Although aware of potential assumptions and discrimination, only a minority of parents appeared to have internalized these assumptions (Super-ordinate theme 4), with reactions to assumptions ranging from anger to resignation.

The extended results presented here add to the previously described thematic structure, with additional themes considered to be important to parents' experiences, although not directly related to the research question [See Figure 5]. For instance, as an extension of Super-ordinate theme 2,



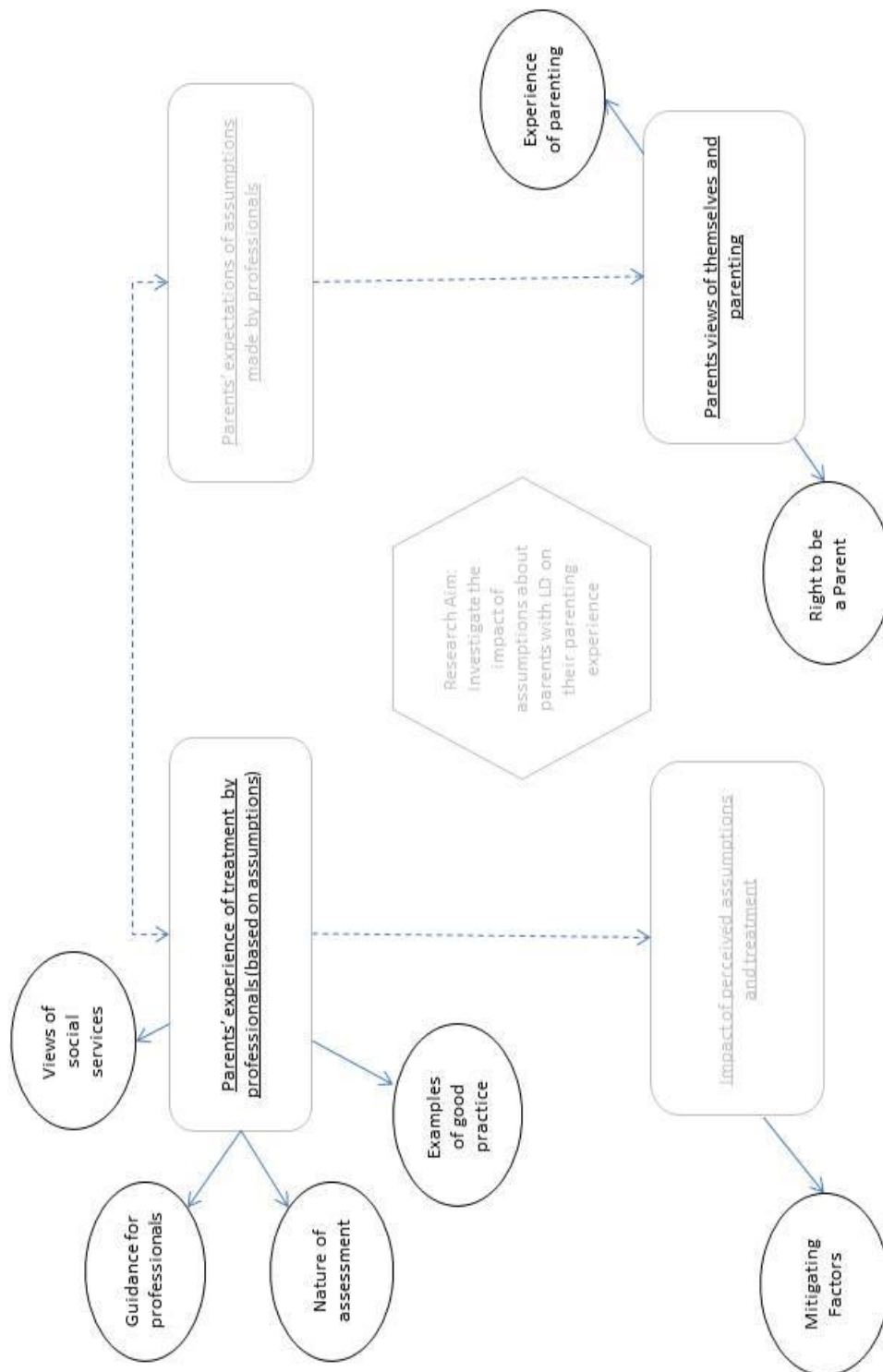


Figure 4: Extended Thematic Map

examples of good practice are considered as an alternative to the negative accounts offered in the main article. Although these instances were given less attention in parents' accounts, they are important to acknowledge due to the beneficial impact such positive relationships had for parents. Also incorporated within this super-ordinate theme is the frequently negative attitude parents had towards social workers as opposed to other professionals, the specific experience of parenting assessments, and a number of recommendations for professionals based on parents' accounts.

In the main results, Super-ordinate theme 3 considered the impact of assumptions on parents. As an additional theme, the potential mitigating factors which determined the extent of the impact on parents are explored. Finally, as an extension of Super-ordinate theme 4, two additional themes are considered, relating to the way parents have experienced parenthood, and their thoughts on their own right, as a person with LD, to be a parent.

### *3.2 Additional themes within Super-ordinate theme 2*

#### *Examples of good practice*

Without exception, the parents could name at least one professional with whom they enjoyed a good relationship, or one example of how services had helped them. This is a reassuring theme, and suggests that in fact changes in attitudes may be taking place, and that parents can indeed distinguish between those professionals who do or do not make assumptions about them. Indeed, several parents noted that they did not perceive the assumptions made about them to extend across all, or even the majority of professionals:

Tommy: Look, what I'm saying is some professionals is up there they are doing the job right and they are trying to listen to people and you get some authorities who are not very good at their job and they making all the other professionals look bad too.

The specific examples of good practice were very individual for each parent, with the common theme that professionals had made them feel supported and valued. Fiona, for instance, valued the few support workers who treated her like a normal person, worthy of conversation:

Fiona: I like the odd one that comes round... We had one come and talk to us about their family, about what they've been doing and that and different ones talk about different things and it's quite interesting to see them go on with their lives and know how they get on with it.

Alan was simply relieved to find a doctor who listened to him and valued his expertise about his son's health problems, following a series of professionals who had not believed him:

Alan: Then we saw this GP called Dr H, really fantastic doctor...So she said, what's the problem? So I told her. Right, give me two minutes, she says, and then she asked me what he was doing and so I told her and everything and she said, yeah, this is not good.

For Greg, good practice was as simple as keeping in touch and keeping him in the loop:

Greg: This one [social worker] is a lot more helpful, she makes sure you got meetings, she rings up how you've been and if she saw Harry, she rings up and tells you how he got on. But the other one don't.

Interestingly, the professional groups singled out most frequently by parents for praise were schools, medical doctors and psychologists.

Schools, for instance, were described as going the extra mile to support parents:

Esther: We asked to see how Samuel's developing and visit and they said they didn't mind, so every so often we see if he's learning a new skill, we go to school and see how he is. That's the interaction we've got and I'm glad we have got that because they write it down on the book on how he's developed.

Psychologists tended to be praised for their individual qualities and the kinds of relationships they maintain with the parents:

Interviewer: I know you've got Sandra [Psychologist] who works with you, have you got anybody else?

Joyce: No, there's only Sandra and you comes out to me, cos I can't trust anybody else.

For three families, doctors were singled out as defending the parents' efforts when their child was ill against strong conflicting opinions:

Alan: And Dr M, he stood our ground, he says, these people were looking after Samuel. It was no-win situation that they was in. Anyway, she said, yes but he could have died and choked, so they are irresponsible. Woah, he hit the roof. He said no, you need to start listening, he says, I am a consultant. Samuel has got so many problems, he could die from his epilepsy that he's got, not from that.

When good practice does occur, it can make a clear difference to families, summed up perhaps by Larry, who hadn't always had the best relationships with professionals:

Larry: Yeah, now they have [provided me with the support I need], yeah definitely leaps and bounds really, it means I can go back to work... All these other people involved and that, That's the best thing really, you know social services and the ones who look after me, they're here to support me as well and like without that, we couldn't have done it.

#### *Recommendations for professionals*

Throughout their stories, the parents made a number of observations for how professionals can work most usefully with them, as well as examples from their experiences of what kinds of treatment and interventions they find work or do not work to support them in their role as parents.

Very few of the parents had been involved with either social services or with LD teams prior to some kind of crisis in their lives. Most parents saw this as a negative thing, as they would prefer to have previously established relationships through early intervention:

Tommy: No one was involved at all. When I phoned them up it was to get me help with my son after he was gone down the wrong road and I tried to get help and no one would listen to me, saying no

there's nothing wrong with Kyle, and then when the social services finally get involved then they find that Kyle have learning disability... and it just went downhill after that you know.

The majority of parents found it useful to have a professional to whom they could turn for advice when necessary:

Esther: We have a lot of involvement with everybody on our team cos if anything we need to query, they're there to help and give us advice and we try it out. If that doesn't work then there's somebody always there to help us.

Support was found to be particularly helpful when it was practical in nature, such as assistance with bills and paperwork. Met with even more enthusiasm was support which enabled the parents to learn:

Danielle: Made fish cakes this week and next time she making a flan with me and I've never made a flan. I'm learning to make fresh food. I can do roast dinners and I make pies and all that, just can't make things that I... I want to make different foods and all that, trying to get my boy a bit fatter.

Parents stressed the importance of professionals making helpful adaptations and taking account of their specific disabilities:

Fiona: I like to learn in me own time, it just made life really difficult cos I like to do it step by step and then child services come to the house and said it wasn't good enough.

Although it may seem obvious, it was clear that the parents responded well to praise, which was severely lacking for some of the parents. In the absence of any positive reinforcement, one of the parents in particular simply stopped trying to do better:

Danielle: Then you're doing the housework then that put me off, really put me doing the housework and I hate doing it now. They all say you're doing things wrong. When you done it right you don't get praise, when you doing something wrong, they put it in their report.

One of the things half the parents were most critical of was the inability of professionals to agree on the best way forward. It left families frustrated at lack of progress and at times simply confused at what was expected of them:

Alan: The condition for being on this child protection thing was that everybody was singing from the same hymn sheet, not all... cos what was happening was one will do that, one will do that, one will do that, one will do that. We didn't know where we was. And it was getting to the stage where, 'I'll just deal with you and nobody else. So, a meeting was called and we all agreed to sing from the same hymn sheet and yeah, things did get better.

On a similar theme, parents appreciated consistency of care, both in terms of keeping the same staff involved in their care when possible, and in maintaining contact with services even when things are going well. This was particularly important because parents acknowledged that they often struggled with the changing needs of their children as they got older, suggesting that support needs to be consistent but flexible:

Interviewer: What do you find difficult about being a dad, if anything?

Tommy: Well keeping up with all the things that the kiddies.....what my sons know about and everything. You know things change every day and you have to keep up with them and keep up with things going on now.

Lastly, parents stressed that they just wanted to be treated fairly and like any other 'normal' parent:

Fiona: I want to be treated like a normal average person, who just goes and sees them from time to time, rather than somebody who's just as though she's got a disability.

### *Nature of assessment*

Given that all the parents had been through Child Protection proceedings at some point in their child's life, they had all been through an assessment of their parenting capacity. Parents' views on the nature of this assessment ranged from it being so unmemorable that they could not remember anything about it, to it being an overly long and invasive process.

One aspect that many parents commented on was the sheer number of professionals involved at meetings:

Alan: So we had the whole world round, we had a big meeting at social services place in there. We've had several in fact. And we had this big meeting, I had Dr M next to me, all the health professionals there that we've used, there was twelve of us. It was like being in court, it really was.

For a few parents, the assessment was simply too complex for them to understand without additional support, particularly because of the nature of language used.

Greg: I don't think I would understand if I didn't have the advocate lady with me. I would be completely lost... Words they're using now, I've never heard of them, you know. They use a more posh word don't they?

Four parents noted how long and invasive the process was:

Alan: It was like being dragged through a hedge, I'm telling you, it was not very nice.

Interviewer: What do you mean? What was?

Alan: Oh everything being dragged... raked up from when you were young and everything. I mean, talk about if they want to look through your files, they will do.

Others focussed on how overwhelming the actual process and meetings could be:

Esther: It was a very trying time cos with all the meetings and with everybody who you know as well and having to explain, then going through all the procedures with the eating and yes it was kind of stressful kind of in a way because there's a lot of talking.

Unsurprisingly given the range of opinions about the nature of the assessment process, parents varied extensively in the extent of the impact they felt from the assessment. All admitted at least a small degree of worry during the process, which is unavoidable, and for some that was the extent of the impact. However, for the majority of parents, they experienced a very high degree of stress during the assessment:

Fiona: I just felt like I'm in a roller coaster ride when you're going up and down and round, you know. I had all these different people and it just made my life hell.

#### *Social workers*

When thinking about different professionals who work with them, social services, and social workers in particular, were the subjects of the most criticism by parents. Half of the parents believed that social workers were simply looking for an excuse to remove their child. For instance, Tommy believes he was not given the chance to attend parenting courses because social workers did not want him to succeed:

Tommy: There had to be loads of classes up there to make me a good parent and not one of them offered me none of that at all. All they wanted is took the kids away. That's the way I feel it is.

Greg similarly felt that social workers took a on a special role during proceedings:

Greg: Yeah, I think it was more with the social workers personally. They was more in the middle of it. You know cos they always have to think of that first... it's their job innit? They always got to think, they always in the middle, you know.

A minority of parents believed that social workers went to extreme lengths, such as lying, to get their children removed:



Interviewer: Why couldn't you stand the social workers?

Joyce: Cos it's them who got Josie took off us, they was told lies all the time to the court.

Two of the parents felt threatened by the social workers:

Danielle: Honestly, I still think they forced me take her in care. I know it's voluntary, but still think they blackmailed me, they said if you don't take her into voluntary care, we'll take you to court and you won't see her at all. That was sort of blackmailing. We didn't want to go through the court thing and all that.

Three of the parents offered their own ideas about why social workers might be providing less helpful support than other professions. Tommy, for instance, believes budget cuts are spreading social workers too thin:

Tommy: What I'm saying is if the social service do their job right I think we're be more better, they are not doing their... they got too many cases and what they're doing, passing the buck over to other people.

Three parents wondered whether a culture of risk aversion and social worker's own fears of consequences, had an impact on their decision making:

Greg: The social workers was a bit of both, can he do it or not do it [look after his child], but you're always gonna get that with them because they could say yes and they could get in trouble over it with their manger... If they brought him back here and he start lashing out then they say, what's he doing here then? They want to know who the social worker. Well it's on the records, they won't be happy with social workers cos they talk to them, they say 'well why did you brought him back then?'.  
 100

### *3.3 Additional themes relating to Super-ordinate theme 3*

#### *Mitigating factors*

The impact of assumptions and treatment for a minority of parents was mitigated by the fact that they didn't consider other people's opinions when making decisions about being a parent:

Interviewer: Did you make guesses about what other people would think about it?

Larry: No, no, no, no. Just get on with it, don't you.

Other parents did think about what others would say and claimed that they did not care. It is important to note that for some parents, this claim did not necessarily match up with the rest of their stories, and this may have been a protective mechanism to claim that they do not care what is thought of them.

Finally, most parents were surrounded by family members who were able to support them and had faith in their parenting abilities, which may have served to lessen the extent to which parents internalised the assumptions:

Interviewer: Did anyone around you say it was a good idea or a bad idea?

Tommy: No they were all, when we tell 'em the news that she's pregnant to all my side of the family, my sister said I make a good father and all that stuff.

### *3.4 Additional themes relating to Super-ordinate theme 4*

#### *Parents' experience of parenthood*

When speaking of their experience of being parents, while some mentioned the continuing difficulty of parenting, the majority focussed on the joy they get from their children:

Esther: It start when you hold in your arms, cos I've always holded me sisters and things like that when they first born and that, and it feels different when you're holding your own and then I felt, yeah, yeah... it was like, I felt really, really happy, you know, from since he was on my chest to holding him and changing him and feeding him and just caring for him, you know, and that.

Only one of the parents remained ambivalent about being a parent:

Interviewer: Do you regret it?

Fiona: Yeah, cos I haven't got much of a life now, I have a little bit of a life, but not much of a life if you know what I mean.

In addition to the joy that most parents expressed about being a parent, the sense of pride at their own achievements shone through. There was a sense of surprise for some parents, suggesting that they had more doubts about their own ability than they tended to admit:

Esther: I know I'm good mum, I'm not boasting or what, but I meant I feel to myself I am a good mum actually, not just cos I've looked after the kids or whatever, no it's just instinct really. I know that I would care for Samuel, giving the best I can give him, and yeah, I think I am a... well, I am a half decent mum.

The picture is mixed amongst parents as to whether they have received sufficient support from professionals overall. While some feel that they are now satisfied with support, others feel let down by services, recognising that with more appropriate support, they could have been better parents and perhaps avoided some disasters along the way:

Greg: You know, if they offered me some more help, it'd be a lot more easy, but sadly it all went pear-shaped but really I did have you know, I did actually, with Harry's social worker, if she didn't make mistakes I think he could be still here all the time now, but now it's too late no, he's got so used to there now.

### *Right to be a parent*

While most of the parents could explain specific things that they found difficult because of their LD, such as multi-tasking, reading, writing, cooking and discipline, the majority believed that these difficulties would not prevent them from being good and capable parents:

Esther: I may not be bright, bright, bright as other people, but it's like I know enough to get by and do things, and not so good in certain areas and that but, like Alan, we help each other out with his weaknesses and my weaknesses, then that makes it a bit easier. So no, that's never been an issue really.

Around half the parents emphasised the idea that everybody, including them, has the right to be a parent. This is exemplified most succinctly by Larry:

Larry: Everyone's got a right to have a kid, even if they have got a learning disability; everyone's got something the matter with 'em.

A lone voice amongst the parents disagreed with this idea. Esther emphasised the rights of the child over the parents:

Esther: If my disability was worse and I knew I couldn't... then we'd do the right thing if we knew that we couldn't look after children cos of our disability then we wouldn't have had Samuel, because you've got to be able to look after a child... but if my disability was worse and if I couldn't look after myself that well, then I don't think I would have had Samuel or any children, cos it wouldn't be fair on them.

## **4. Extended Discussion**

### *4.1 Extended discussion of main findings*

Figure 3 (cited in the journal paper above) depicts a potential negative cycle of assumptions and mutual suspicion between parents with LD and the professionals supporting them. In part, this supports the model proposed by Feldman (2002) to explain the relationship between stigma, social support,

parental health and child outcome. Although there is currently limited evidence to confirm the existence of this cycle overall, many of the stages are well-supported. That stigma can lead to increased levels of stress is well-established (e.g. Corrigan & Watson, 2002). There is also a link between the expectation of discrimination and unwillingness to access healthcare services within mental health populations (e.g. Burgess, Ding, Hargreaves, van Ryn & Phelan, 2008). There is no reason to assume that the threat of discrimination should not also make it less likely for parents with LD to engage with services. It is clear that both of these outcomes (increased stress and decreased available support) can have a direct impact on parenting performance and child outcomes (Feldman et al., 2002), which may serve to reinforce the recognised expectation that parents with LD will not be able to cope (Booth, Booth & McConnell, 2004). If this belief is indeed strengthened in professionals, and their belief that parents could cope with the right support is correspondingly reduced, Azjen's (1991) theory of planned behaviour would indicate that they may in fact reduce their intended levels of helping behaviour accordingly. This potential change in behaviour would understandably activate parent's fear of discrimination, and feed directly back into the negative cycle.

#### *4.2 Discussion of additional themes*

Parents found the assessment process in particular a harrowing experience. This is to be expected given the implications of an assessment, yet when describing their difficulties, parents focussed on aspects which could in fact be adapted in order to cause less distress. For instance, parents commented on the overwhelming number of professionals attending meetings, the length and intrusive nature of the assessment, the complexity of language used by professionals and the lack of transparency involved in the process. This is entirely consistent with previous accounts of assessments by parents with LD (Booth & Booth, 2005; Tarleton, Ward & Howarth, 2006). It suggests that, despite calls from policy makers to improve the consistency and efficiency of the assessment process, parents are not experiencing any change in the reality of assessment. Of course, it will not be possible to remove all stress from assessments of parenting, as the consequences of the outcome of assessment may mean the removal of a child from the

family unit. However, previous authors have made suggestions to minimise the distress of an assessment (Booth & Booth, 2005), very few of which appear to have been adopted for parents in the current research.

All of the parents described examples of positive practice from professionals, which should not get lost in the passion with which they spoke of negative practice. With the introduction of government policy, such as 'Good Practice Guidance', it would be expected and hoped that negative attitudes towards parents are becoming decreasingly prevalent and acceptable. Indeed, studies examining attitudes in professionals suggest that the majority of professionals hold liberal attitudes towards sexuality and parenthood in people with LD (Evans, McGuire, Healy & Carley, 2009), which is endorsed by the parents' ideas that they have experienced negative assumptions in only a proportion of professionals. This finding fits as well with Deeley's (2002) finding that old paternalistic attitudes are gradually being superseded by ideas of normalization as younger, new professionals enter services. Although this is encouraging, it does not alter the reality parents face at present.

The results of the current study suggested variability amongst professional groups in the degree to which they are influenced by assumptions. The prevailing sense was that social workers were cast as villains, while psychologists and medical doctors were cast in almost an advocacy role. While this might reflect differing attitudes towards parents with LD, this result should be interpreted with caution. Social workers tend to have a very different role in assessments and care proceedings, and can become a figure-head for a wider multi-disciplinary team. Additionally, the social workers involved in such cases are frequently child social workers rather than LD social workers, who may have less experience of working with people with LD. This is borne out by Goodinge (2000), who noted that of around 60 parents with LD who were on child protection, 84% had a child social worker as their named key worker. This was substantially higher than for a larger sample of disabled parents in general, where only 28% had child social workers as keyworkers. It might be hypothesised that, if child social workers have limited experience working with people with LD, they might be more susceptible to making invalid assumptions about their

ability. Equally, they might simply be less skilled at adapting their practice for the specific needs of an LD population, leading to incorrect labelling of the practice as based on assumptions. A final hypothesis was proposed by the parents themselves: social workers may be more cautious about risk, due to a culture of blame within social services. This has been discussed by a number of authors in the wake of high profile child protection cases (e.g. Beddoe, 2010, Carey, 2012).

#### *4.3 Extended critique*

It is acknowledged that parents were able to present an entirely subjective account of their experiences. Particularly with some of the accounts provided, it is expected that the professionals involved may have presented an entirely differently account. Although it may have been possible to use a form of triangulation, to corroborate or disconfirm parents' accounts, as used by Pixa-Kettner (1999), the critical realist epistemology allows for multiple versions of reality around a single event to exist. It is therefore accepted that the parents have provided true and valid accounts of their own experiences, which is crucial for understanding their subsequent reactions, while noting cautiously that professionals might interpret events differently.

A further potential weakness of the study was in the potential for researcher bias during the interview process, specifically due to the vulnerable nature of the population. Porter and Lacey (2005) noted that where parents with LD perceive a power imbalance in interview settings, they are likely to acquiesce to the researchers' own implicit beliefs. This risk was attended to during the current research, with the interviewer paying careful attention to their own physical and verbal responses to parents' views. Additionally, the possibility of acquiescence was kept in mind through the phrasing of the questions, and through checking each participant's willingness to say 'No' to leading questions.

A final potential difficulty with the research was the range of ages of children (up to 16 years old) within the sample. This introduced the possibility that parents could have been describing circumstances across a long time period, during which attitudes and approaches to practice may

have changed. However, all parents discussed events and feelings in relation to the present day, and with one exception (Joyce), services had only carried out parenting assessment in the context of the parents' LD within the previous two to three years, and certainly after the introduction of 'Good Practice Guidance' in 2006.

Despite the potential limitations of the research, it offers an important examination of the awareness and impact of outdated assumptions on parents with LD, which has not previously been explored. In addition to the novelty and appropriate timing of such research, a number of factors add to the strength of the findings. Firstly, care has been taken throughout the research process to make decisions transparent and to minimise the influence of the author's pre-conceptions on the construction of the results. This has led to an account which is faithful to parents' experiences. The inclusion of participants from three different NHS trusts also represents a strength of the research: even though the three trusts offer very different levels of support for parents, there was no clear distinction in parents' accounts of assumptions. This suggests that the difficulties they have encountered are more widespread and not merely limited to staff within a single region. The inclusion of only parents who had maintained custody of their children is also a strength of the study. Although they represent a small proportion of parents with LD known to services, the fact that they have children living at home mitigates to some extent, the possibility that professionals are making correct assumptions that they are inadequate parents. Finally, the research is unusual in addressing a relatively complex notion with people with LD from a qualitative perspective. The research question required parents to put themselves in the position of another person, make guesses about the way they were thinking and feeling, link their assumptions to their behaviour, and assess the impact on their own emotions and behaviour. All of these steps represent potentially difficult tasks for a person with LD and as such, research has tended to ignore such areas in this population. Through particular care to the style of interview, the phrasing of the questions and relationship between interviewer and interviewee, the current research was able to overcome such difficulties.



#### *4.4 Transferability of Findings*

Although the sample size for the current research was considered adequate for this method of analysis, the small sample sizes used for qualitative research in general bring in to question the strength and wider applicability of the results. The study overcame some potential limitations through the representativeness of the sample. Unlike the vast majority of research into parents with LD (Robb, 2004), the research provided the opinions of fathers as well as mothers with LD.

The study also aimed to recruit a homogenous sample, in order to provide a meaningful account of a particular phenomena in a particular context (Smith & Osborn, 2003). The fact that all the parents had retained custody of at least one child following parenting assessment by services ensured a relatively homogenous sample. Equally, all parents were known to have mild learning disabilities, rather than borderline LD, which is often not the case in LD research, ensuring the sample was in fact representative of a population of parents with LD. However, even within such a specific group, it is never possible to find absolute homogeneity. The parents included in this sample, for instance, differed in key areas such as: the quality of support available in their local area; the health of their children; and their expressive language ability, each of which might influence their relationship with services.

This relative homogeneity of sample does reduce the extent to which results can be transferred to other samples. For instance, it is entirely possible that a group of parents with LD who had been assessed by services, and lost custody of their children as a result, may have presented a more negative account of services. Equally, given the substantial variability in service provision for parents with LD throughout the UK, the results might only be applicable to parents living in Norfolk, Lincolnshire and Nottinghamshire. However, the results of this study could be useful in providing a basis of knowledge of professionals working with all parents with LD, as long as results are transferred across groups with caution.

#### *4.5 Implications and recommendations*

The results of this study are relevant to clinical practice in a number of ways, particularly in terms of the potential impact on parenting adequacy in people with LD, the way they engage with services and the way professionals interact with parents with LD. Feldman (2002) proposed that stigma can influence parenting success both through diminished mental health and altered treatment by services. In order for stigma to affect mental health, a person needs to be aware of stigma, and the current research offers the first evidence that parents with LD are indeed aware of negative assumptions. Given that many parents described the impact on their mental health, it is clear to see that their parenting ability might be negatively impacted by the existence of such assumptions. Similarly, the parents within this sample would endorse Feldman's proposal that they receive less helpful treatment due to professionals' assumptions. Given this scenario, it is particularly important that such perception of stigma is addressed. This might come in a number of forms: training for professionals in debunking the myths surrounding parents with LD; an increase in resources available to professionals to support parents with LD, including availability of specialist parenting courses, and appropriate assessment tools; availability of advocates for parents with LD to redress the inherent power imbalance in their interactions with services.

It is acknowledged throughout the research that parents are presenting subjective accounts of their experience. While they perceive professional behaviour to be influenced by their stereotypical assumptions, this does not necessarily reflect professional attitudes. Nevertheless, some aspects of professional behaviour are consistent with parents' expectations, reinforcing their perception of assumptions. It is therefore likely that if professionals were able to behave in a manner which did not reinforce such perceptions, parents' experience of stigma would be reduced. A number of examples were extracted from parents' accounts to form recommendations for professional interaction that might promote trust and engagement with services. These included the use of praise, using appropriate language and being clear and specific in instructions. All of these are elements of practice which would be routine to practitioners familiar with working with people

with LD. It seems therefore, that designating staff from specialist LD teams rather than Child Services as a keyworker in parenting assessments would lead to interactions with services which are less likely to trigger perceptions of discrimination.

In terms of future research, a number of possible avenues could be explored. The main paper highlights future research to investigate Feldman's (2002) parenting model as well as the individual differences that might influence professionals' attitudes towards parents with LD. However, at a more basic level, it will be important to investigate professionals' own ideas about the presence of specific assumptions in themselves and in colleagues. However, this is likely to prove difficult due to the effects of social desirability. Additionally, the current research focuses purely on parents who have maintained custody of their children. It seems likely that those parents who have lost custody would have had an even more negative experience with services, and it would be interesting to consider to what extent the perception of negative assumptions had contributed to the breakdown of their parenting.

#### *4.6 Good Practice Guidelines*

Based on the above research, the following guidelines for good practice have been developed for practitioners working to support parents with LD. The guidelines do not advise on the actual decision-making process in the assessment of parenting, but offer suggestions on way professionals interact with parents with LD to ensure parents have the best chance of parenting successfully.

##### *Assessment process*

- The process should be as brief and transparent as possible
- Assessment meetings should be conducted with the minimum sufficient professionals to avoid overwhelming parents
- Written material should be adapted to suit the ability of parents, as should the language used by professionals during meetings
- Assessments should focus on strengths as well as risks

- Parents with LD should not be expected to meet a higher standard of parenting than the rest of the population
- The assessment should be led by an experienced LD professional

#### *Nature of interaction and support*

- It should be made clear to parents that they will not automatically lose their child due to their LD
- Wherever possible, maintain consistency of professionals involved – where change is enforced (e.g. staff member leaving team) a thorough handover should be undertaken
- Goals to improve parenting should be clear, specific and collaborative
- Incremental achievements and parental engagement should be rewarded with praise and encouragement
- Do not withdraw support completely even when the situation appears stable, recognising that needs change as the child develops
- Professionals should consider whether lack of parental engagement is based on fear of discrimination

#### *Empowered parents*

- Treat parents with respect and as an 'expert' on their own children
- Encourage parents to make decisions rather than dictating their actions
- Recognise that parenting styles are individual and need not be uniform
- Offer training in skills parents wish to develop (e.g. cooking)
- Allow sufficient time at meetings to ensure that parent's voices are heard in all aspects of support

## **5. Critical Reflection**

As discussed in section 2.6, the epistemological position of this study was one of critical realism, which fits closely with the chosen method of analysis. Within this position, there is acknowledgement that when thinking about an event, there might be multiple versions of the truth, influenced by the individual's prior experiences and beliefs. In terms of the analytic process therefore, it is acknowledged that the researcher will bring their own constructed beliefs and experiences, through which the meanings will be interpreted. For the researcher, their understanding of the individuals' stories might be influenced by not only their own personal experiences, but also their prior knowledge and theoretical understanding. This has clear implications in terms of the objectivity of qualitative research, as the specific background of the researcher will bring different pre-conceptions to the study. This position of the researcher within the research is commonly emphasised, particularly in IPA, as a double hermeneutic. However, in the case of this research, it might be thought of as even more complex, as the researcher is attempting to make sense of the parents trying to make sense of the professionals trying to make sense about them. Thus, it will be important to keep in mind what might influence the researcher not only with regard to the parents, but also with regard to the professionals.

While attempts can be made to limit the impact of these pre-conceptions and to ensure the validity of the interpretation, complete objectivity is never possible, meaning that any analysis becomes a co-construction between the researcher and the research participants. In order to monitor and acknowledge the extent and impact of the researcher's position, a reflective diary was kept by the researcher throughout the process and will now be discussed using supporting extracts. The question that arose for me most often during the process of this research was whether I made my own assumptions about parents with LD. My opinion coming into the research was perhaps best described as ambivalent and I attempted to explore the origins of my attitudes towards people with LD as parents in the following journal extract:

I was raised in a family in which the family business was running a residential care home for people with LD. It was an incredibly warm and loving environment for the residents, and while I grew up, they became almost a part of my extended family. The home seemed to me a good balance of protecting and caring for those most vulnerable in society, while promoting their choice and independence, long before it became fashionable to do so. However, there was a degree of practically mixed in: for instance, the recognition that too much choice could overwhelm rather than inspire. Looking back, this might have been perceived as a kind of paternalistic approach to their care. Certainly, there was never any question that those living there would be able to raise children or even fully explore their sexuality.

To reconcile this protective yet limiting attitude with my, at times, staunch advocacy of the right of parents with LD to raise children, I think I must draw on my previous work as an assistant psychologist in various LD teams. I had seen first hand parents' efforts to succeed and the desperate love they had for their children. To then hear professionals discussing them in such disparaging terms triggered in me a sense of injustice on their behalf. And so I remain on the fence, in a sense. I believe services should be aware of the risk that parents might find it more difficult to be a parent, but that it should be treated as a risk rather than a certainty. The mission should be to provide sufficient support to ensure that parents can't fail, rather than say 'Why spend all that money, when they're not going to cope in the end anyway'.

When designing the research, I had to consider whether the questions I was intending to ask would be simple enough to be understood by the participants and whether the answers I could elicit could be substantial enough to address my research aims. This selection from the reflective diary was written following a meeting with my field supervisor who doubted whether it could be successful:

I am beginning to agree that I may have set myself a really difficult task. To ask people with LD what assumptions they make about the

assumptions professionals are making about them, is tricky to say the least. It has proved difficult enough for me to phrase this in a way that is comprehensible to course tutors. My experiences working with people with LD leave me believing that it is possible, but that I will have to be extremely careful in the way I word the questions. There have certainly been a lot of people I have worked with therapeutically who would not have been able to answer such a question. Some have not had the verbal language skills to entertain the discussion. Other people with LD have not been able to put themselves in the position of another person and imagine their thoughts. If they can't achieve this, am I asking anything of any use?

It would have been incredibly useful to pilot the interview schedule with a person with LD, but that raised too many issues, not least of which is that it may not have told me anything. 'People with learning disabilities' do not represent a homogeneous category where if one person can understand a question, they all will. So the next best thing was to role-play the interview with someone who has worked with people with LD for several decades. I asked them to think back to a parent with LD they had known and answer my questions from their perspective. It was a disaster. The test subject was very effective in their role, and struggled to answer any of the direct questions I asked. This has emphasised for me that I need to start with concrete areas and move through to more abstract ideas to give the parents the best chance at telling their stories.

I also wonder about the kind of stories I might hear from parents. I know from my previous experience that going through child protection proceedings can be an incredibly distressing process and this might well colour all recollection of interactions with professionals. I don't think parents will hold back from being honest about their experiences, but I hope that by using a sample of parents who have kept their children, that they might be protected somewhat from accusations of bias in their perspectives of professionals. Either

way, parent's opinions in the interviews will be their versions of the truth.

As well as my previous experience, I considered whether my current role as a trainee clinical psychologist might have an impact on the process of data collection, in the way I ask questions, in the way I respond to answers and in the kinds of stories parents might want to tell me. I reflected on this in a diary entry in the lead-up to the first interview:

With my first interview coming up in a few days time, I have been thinking about my role in the interview. I really want it to go well, and by this, I think I mean that I want parents to understand what I am asking, and I want them to have something interesting to say in relation to my research aims. However, I am aware that I want the interviews to go well for the purposes of passing my thesis. I know I have to keep that in mind or run the risk of biasing my interviews in my quest to get the 'right' answer, or one that matches my own beliefs. This is a particular danger with this client group, who are known to be more susceptible to leading questions and acquiescence. As much as the questions I ask, I am concerned about the way I respond to the parent's stories. As a trainee psychologist, my background is as a clinician rather than a researcher, and I wonder if I will be able to switch off that stance of unconditional positive regard and become a more neutral interviewer. Is that even the right perspective to take with this client group? When I have only one session with a client group who might well have had distressing interactions with professionals, would it be right not to respond empathically to their stories?

Finally, I wonder if simply the idea that I am a 'psychologist' coming to talk to these parents might influence the stories they choose to tell me. Parents with LD are known to be a particularly socially isolated group, and the chance to have someone listen uninterrupted for an extended period might be too good to pass up. Given that a psychologist is someone that you tell your problems to, will they choose to focus simply on the negatives of working with professionals



rather than the positive? Does it matter if they do? I want to hear about the assumptions that professionals might make and this is automatically likely to divert the interview to negative areas, I can't imagine there being many positive assumptions. However, I need to make sure that parents feel they can tell positive stories if that is their experience.

Once the interviews had started, my opinions of the potential of the research and my own attitudes towards parents with LD fluctuated from interview to interview. I also considered how my feelings about the parents might influence my interpretation of the data. I collected my thoughts after interviews three, six and ten, in the following three extracts:

[After interview three] My first thought having conducted the first three interviews is that this might be a struggle. I can't help but feel that the interviews have not gone well. I have certainly established a good rapport with all of the parents, in fact one of the parents stated that there was only myself and one other professional who she would trust enough to let in the house. However, I wonder if I have allowed the parents to tell their stories in the best way possible. There are clear issues of understanding for the parents. One parent often answered a different question to the one I had asked, and I found myself frequently checking back that she had understood my questions. Although she always said that she had, I wonder if this was an example of her acquiescing and not feeling confident enough to say she had not understood. With the other couple I interviewed, I was left very frustrated. When I had visited them to obtain informed consent, they had talked avidly of their experiences with professionals, both positive and negative. When I returned to complete the interview, they were similarly animated. However, as soon as I switched on the recording equipment, they became very reticent, claiming not to remember past events. I cannot find a good explanation for this, as it was not deliberately obstructive. It might have simply been that there was too much performance anxiety once the interview started.

[After interview six] Three interviews later and I am far more satisfied with how the interviews are progressing. My major concern has always been making sure that parents can understand my questions without being too leading, and I feel confident this has been achieved. I don't know, however, if that is because I am asking the questions in a more appropriate way, or whether these parents have been more able. However, for the first time, I came out of an interview concerned for the well-being of the child. I felt very despondent today, in fact, as I wondered if I was displaying the assumptions about a parent with LD that I would normally say are doing a disservice to parents with LD. In previous interviews, I had noted that some parents' houses might have been untidy (although not all of them) and that some (but not all) parents had limited verbal ability. These situations had not triggered any assumptions for me about their ability as parents. If you took a sample of any parents, LD or not, you would find those who lived in untidy houses, or struggled to provide a stimulating environment for their children. In fact, this latter point could be attributed as much to busy professional parents who never had time for their children. Today, however, I seriously questioned the suitability of the environment, I felt judgemental of the state of her house and the way she interacted with her children. The only way I can rationalise this is that all the other parents expressed such love and determination to do their best for their children, whereas today's parent expressed such ambivalence. Perhaps this made it more difficult for me to see the positives.

[After interview ten] I have just finished my final interview, and more than anything, I have been struck by the honesty and openness of these parents. I felt myself making links to the earlier interviews, so it seems I have already begun to interpret the data. With some of the parents, I was astounded that their parenting ability had ever been questioned, as their dedication and love for their children shone through. I was perhaps more surprised at the eloquence with which most of the parents expressed themselves: they could easily tell me

what they thought other people might think about them, and whether they thought professionals attitudes influenced their behaviour. I have been so moved by some of the parents stories, particularly when one parent described the moment her son died in her arms. I feel so much that I want to represent the parents' stories in a way that stays faithful to their meaning, but I need to be aware that I might have internalised some of their anger towards professionals, so that could have an impact on how I analyse the data. In fact, most of the parents were incredibly gracious about maintaining an open mind about professionals, and I need to reflect that.

When analysing the data gathered and choosing the quotes to support the themes created, a different set of concerns were raised for me: the process of using the actual words of parents to back up a position I have extracted provoked surprising feelings of anxiety, as was discussed in the following journal extract:

Throughout this process, I have been comfortable with the idea that I am hearing the parents' truth. However, coming today to group quotes together into themes, I started to question the fairness of that. I saw, for instance, that social workers took a particular battering, and it suddenly felt difficult that they were not able to defend themselves against accusations of lies, threats and personal missions to remove the children of parents with LD. I found myself considering whether parents were being accurate in their accounts, and whether I would be propagating some kind of falsehood by classifying it as a theme. Without triangulating the data in some way, there would be no way to assess which account was 'real'. However, my doubts were allayed to some extent by thinking about my epistemological position. Critical realism accepts that, while there may be one 'reality', independent of individual's cognitions, there can exist multiple, legitimate perspectives of this reality, which are just as valid to consider. This was how parents had experienced reality, and which had real implications to the way they felt and reacted.

I also hope that I use parents' words in a way that they would feel represents their meaning. I have found a difficulty in wanting to use entire chunks of text, as without the context, some of their complex meanings can be lost, yet complying to such mundane ideas as word counts. I also need to ensure that I can maintain the parents' confidentiality, especially since they have been so honest and open about the people who will continue to support them. This might prove difficult, since there are so few parents involved with services who still have their children at home. For anyone working with them, it could prove easy to identify them, unless I choose quotes and provide information with care.

### References for Extended Paper

- Accardo, P. J., & Whitman, B. Y. (1989). Factors influencing child abuse/neglect in children of mentally retarded parents. *Pediatric Research, 25*, 95.
- Ajzen, I. (1991). The theory of planned behavior. *Organizational behavior and human decision processes, 50*(2), 179-211.
- Alcorn, D. E. (1974). Parental views on sexual development and education of the trainable mentally retarded. *Journal of Special Education, 8*, 119-130.
- Aunos, M., Goupil, G. & Feldman, M. (2008). Mothers with intellectual disabilities who do or do not have custody of their children. *Journal on Developmental Disabilities, 10*(2), 65-79.
- Aunos, M., & Feldman, M. A. (2002). Attitudes towards sexuality, sterilization and parenting rights of persons with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(4), 285-296.
- Barker, D. (1989). The biology of stupidity: Genetics, eugenics and mental deficiency in the InterWar years. *The British Journal for the History of Science, 22*, 347-375
- Barker, L. T., & Maralani, V. (1997). *Challenges and strategies of disabled parents: Findings from a national survey of parents with disabilities*. Oakland, California: Berkeley Planning Associates for Through the Looking Glass.
- Baum, F. (2002). *The New Public Health*, (2nd Ed). Melbourne: Oxford University Press.

- Beddoe, L. (2010). Surveillance or reflection: Professional supervision in 'the risk society'. *British Journal of Social Work*, 40(3), 1-18.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 47-56.
- Belsky, J. (1984). The determinants of parenting: A process model. *Child development*, 83-96.
- Bhaskar, R. (1998). Philosophy and scientific realism. *Critical realism: Essential readings*, 16-47.
- Bisman, J. (2010). Postpositivism and accounting research: A (personal) primer on critical realism. *Australasian Accounting Business and Finance Journal*, 4(4), 3-25.
- Booth, T. (2003). Parents with learning difficulties and the stolen generation. *Journal of Learning Disabilities*, 7(3), 203–209.
- Booth, T. & Booth, W. (1994). *Parenting under pressure: Mothers and fathers with learning difficulties*. Buckingham: Open University Press.
- Booth, T. & Booth, W. (1996). Sounds of silence: narrative research with inarticulate subjects. *Disability and Society*, 11(1), 55-69.
- Booth, T. & Booth, W. (1997). Making connections: a narrative study of adult children of parents with learning difficulties. *Doing disability research*, 123-143.
- Booth T. & Booth W. (1998). *Growing up with parents who have learning difficulties*. London: Routledge.
- Booth, T., & Booth, W. (2000). Against the odds: growing up with parents who have learning difficulties. *Mental Retardation*, 38(1), 1-14.

- Booth, T. & Booth, W. (2004). *Parents with Learning Difficulties: child protection and the courts, a report to the Nuffield Foundation on Grant No. CPF/00151/G*. Sheffield University: Department of Sociological Studies.
- Booth, T., & Booth, W. (2005). Parents with learning difficulties in the child protection system Experiences and perspectives. *Journal of Intellectual Disabilities*, 9(2), 109-129.
- Booth, T. & Booth, W. (2006). The uncelebrated parent: stories of mothers with learning difficulties caught in the child protection net. *British Journal of Learning Disabilities*, 34, 94-102.
- Booth, T., Booth, W., & McConnell, D. (2004). Parents with learning difficulties, care proceedings and the family courts: Threshold decisions and the moral matrix. *Child and Family Law Quarterly*, 16(4), 409-421.
- Booth, T., Booth, W. & McConnell, D. (2005). Care proceedings and parents with learning difficulties: comparative prevalence and outcomes in an English and Australian court sample. *Child and Family Social Work*, 10(4), 353-360.
- Boursnell, M. (2012). Assessing the capacity of parents with mental illness: Parents with mental illness and risk. *International Social Work*.
- Bowden, K. (1994). Parents with intellectual disability. *Adelaide Healthy Families, Healthy Children Conference, CAFHS Forum*, 2(4), 19-24.
- Boyatzis, R. E. (1998). *Transforming qualitative information: Thematic analysis and code development*. Thousand Oaks, CA: Sage.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.

- Brewer, M. B., & Brown, R. J. (1998). *Intergroup relations*. McGraw-Hill.
- British Psychological Society (2000). *Learning disability, definitions and contexts*. Leicester: The British Psychological Society.
- Brock, L. F. (1934). *Report of the Departmental Committee on Sterilisation*. London: Ministry of Health of Great Britain.
- Buck v. Bell (1927). 274 U.S. 200. Retrieved from <http://laws.findlaw.com/us/274/200>
- Buetow, S. (2010). Thematic analysis and its reconceptualization as 'saliency analysis'. *Journal of Health Services Research & Policy*, 15(2), 123-125.
- Bunge, M. (1993). Realism and antirealism in social science. *Theory and Decision*, 35(3), 207-235.
- Burgess, D. J., Ding, Y., Hargreaves, M., van Ryn, M., & Phelan, S. (2008). The association between perceived discrimination and underutilization of needed medical and mental health care in a multi-ethnic community sample. *Journal of health care for the poor and underserved*, 19(3), 894-911.
- Carey, M. (2012). Mind the Gaps: Understanding the rise and implications of different types of cynicism within statutory social work. *British Journal of Social Work*. Doi: 10.1093/bjsw/bcs098.
- Carlson, G., Armitstead, C., Rodger, S. & Liddle, G. (2010). Parents' experiences of the provision of community-based family support and therapy services utilizing the strengths approach and natural learning environments. *Journal of Applied Research in Intellectual Disabilities*, 23, 560-572.



- Carr, A. & O'Reilly, G. (2007). Diagnosis, classification and epidemiology. In: A. Carr, G. O'Reilly, P. Walsh, & J. McEvoy (eds). *Handbook of intellectual disability and clinical psychology practice*. London: Routledge.
- Cleaver, H., & Nicholson, D. (2003). *Learning disabled parents and the Framework for the Assessment of Children in Need and their Families*. London: Royal Holloway, University of London.
- Cleaver, H. & Nicholson, D. (2007). *Parental learning disability and children's needs: Family experiences and effective practice*. London: Jessica Kingsley Publishers.
- Cleaver, H., & Walker, S. (2004). From policy to practice: the implementation of a new framework for social work assessments of children and families. *Child & Family Social Work*, 9(1), 81-90.
- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27-35.
- Corrigan, P. W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology Science Practice*, 7, 48-67.
- Corrigan, P. W., Faber, D., Rashid, F., & Leary, M. (1999). The construct validity of empowerment among consumers of mental health services. *Schizophrenia Research*, 38, 77-84.
- Corrigan, P. W., Larson, J. E., & Rusch, N. (2009). Self-stigma and the "why try" effect: impact on life goals and evidence-based practices. *World Psychiatry*, 8(2), 75-81.
- Corrigan, P. W., & Watson, A. C. (2002). The paradox of self-stigma and mental illness. *Clinical Psychology: Science and Practice*, 9(1), 35-53.

- Crabtree, B. F., & Miller, W. L. (1999). Using codes and code manuals: a template organizing style of interpretation. *Doing qualitative research, 2*, 163-177.
- Crawford, J. R., Gray, C. D., & Allan, K. M. (1995). The WAIS – R (UK): Basic psychometric properties in an adult UK sample. *British Journal of Clinical Psychology, 34*, 237–250.
- Cunningham, C. C., Glenn, S., & Fitzpatrick, H. (2001). Parents telling their offspring about Down Syndrome and disability. *Journal of Applied Research in Intellectual Disabilities, 13*(2), 47-61.
- Danermark, B., Ekstrom, M., Jakobsen, L., & Karlsson, J. C. (2002). *Explaining reality: Critical realism in the social sciences*. London: Routledge.
- Davies, C. A., & Jenkins, R. (1997). 'She Has Different Fits to Me': how people with learning difficulties see themselves. *Disability & Society, 12*(1), 95-110.
- Deeley, S. (2002). Professional Ideology and learning disability: an analysis of internal conflict. *Disability and Society, 17*(1), 19-33.
- Department of Health (2000). *Framework for the assessment of children in need and their families*. London: Stationery Office.
- Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st Century*. London: The Stationary Office.
- Department of Health (2007). *Good practice guidance on working with parents with a learning disability*. London: The Stationary Office.
- Department of Health and Social Security (1971) *Better services for mental handicap*. London: HMSO.

- Dixon-Woods, M., Shaw, R. L., Agarwal, S., & Smith, J. A. (2004). The problem of appraising qualitative research. *Quality and Safety in Health Care*, 13(3), 223-225.
- Dowdney, L., & Skuse, D. (1993). Parenting provided by adults with mental retardation. *Journal of Child Psychology and Psychiatry*, 34(1), 25-47.
- Dunn, L., Nowrangi, M., Palmer, B., Jeste, D., & Saks, E. (2006). Assessing decisional capacity for clinical research or treatment: a review of instruments. *American Journal of Psychiatry*, 163(8), 1323-1334.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and empowering families: Principles and guidelines for practice*. Cambridge, MA: Brookline Books.
- Edgerton, R. B., & Bercovici, S. M. (1976). The cloak of competence: Years later. *American Journal of Mental Deficiency*, 80, 485-497.
- Ehlers-Flint, M. L. (2002). Parenting perceptions and social supports of mothers with cognitive disabilities. *Sexuality and Disability*, 20(1), 29-51.
- Emerson, E., Hatton, C., Robertson, J., Roberts, H., Baines, S., & Glover, G. (2010). *People with Learning Disabilities in England: 2010*. Durham: Improving Health & Lives: Learning Disabilities Observatory.
- Espe-Sherwindt, M. & Kerlin, S. (1990) 'Early intervention with parents with mental retardation: do we empower or impair?' *Infants and Young Children*, 2, 21-8.
- Evans, D. S., McGuire, B. E., Healy, E. & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part

II: staff and family carer perspectives. *Journal of Intellectual Disability Research*, 53, 913–921.

Faureholme, J. (2006). You've got to fight: Children growing up in families of parents with intellectual disabilities. In G. Llewellyn et al., *Parents with Intellectual Disabilities: past, present and futures*. Sussex: Wiley & Sons.

Feldman, M. (1994). Parenting education, for parents with intellectual disabilities: A review of outcome studies. *Research in Developmental Disabilities*, 15, 299-332.

Feldman, M.A. (2002). Parents with intellectual disabilities and their children: Impediments and supports. In. D. Griffiths & P. Federoff (Eds.) *Ethical dilemmas: Sexuality and developmental disability* (pp. 255-292) . Kingston, NY: NADD Press.

Feldman, M. A., Ducharme, J. M., & Case, L. (1999). Using self-instructional pictorial manuals to teach child-care skills to mothers with intellectual disabilities. *Behavior modification*, 23(3), 480-497.

Feldman, M. A., Leger, M. & Walton-Allen, N. (1997). Stress in mothers with intellectual disabilities. *Journal of Child and Family Studies*, 6, 471–485.

Feldman, M., Varghese, J., Ramsay, J., & Rajska, D. (2002). Relationship between social support, stress and mother-child interactions in mothers with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 314-323.

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods*, 5(1), Article 7.

- Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability & society*, 13(1), 37-51.
- Fiske, S. T. (1998). Stereotyping, prejudice, and discrimination. In D. T. Gilbert, S. T. Fiske, & G. Lindzey (Eds.), *The handbook of social psychology* (4th ed., pp. 357–411). Boston: McGraw-Hill.
- Fiske, S. T. (2000). Stereotyping, prejudice, and discrimination at the seam between the centuries: Evolution, culture, mind, and brain. *European Journal of Social Psychology*, 30(3), 299-322.
- Floor, L., Baxter, D., Rosen, M., & Zisfein, L. (1975). A survey of marriages among previously institutionalized retardates. *Mental Retardation*, 13(2), 33-37.
- Gallagher, Andrea (2011) *Investigating staff's attitudes and willingness to support men and women with mild intellectual disabilities on matters relating to their sexuality*. D Clin Psy thesis, University of Glasgow.
- Giallo, R., Cooklin, A., Wade, C., D'Esposito, F., & Nicholson, J. M. (2013). Maternal postnatal mental health and later emotional-behavioural development of children: the mediating role of parenting behaviour. *Child care, health and development*. doi: 10.1111/cch.12028
- Gilbert, T. (2004). Involving people with learning disabilities in research: issues and possibilities. *Health & social care in the community*, 12(4), 298-308.
- Gillberg, C., & Geijer-Karlsson, M. (1983). Children born to mentally retarded women: a 1-21 year follow-up study of 41 cases. *Psychological Medicine*, 13(4), 891-894.

- Gilmore, L., & Chambers, B. (2010). Intellectual disability and sexuality: Attitudes of disability support staff and leisure industry employees. *Journal of Intellectual and Developmental Disability, 35*(1), 22-28.
- Glasman, L. R., & Albarracín, D. (2006). Forming attitudes that predict future behavior: A meta-analysis of the attitude-behavior relation. *Psychological bulletin, 132*(5), 778.
- Glaun, D. E., & Brown, P. F. (1999). Motherhood, intellectual disability and child protection: Characteristics of a court sample. *Journal of Intellectual and Developmental Disability, 24*(1), 95-105.
- Goddard, H. (1912) *The Kallikak Family: A study in the heredity of feeble-mindedness*. New York: Macmillan.
- Goodinge, S. (2000). *A jigsaw of services: Inspection of services to support disabled adults in their parenting role*. London: Social Services Inspectorate, Department of Health.
- Grieve, A., McLaren, S., Lindsay, W., & Culling, E. (2008). Staff attitudes towards the sexuality of people with learning disabilities: a comparison of different professional groups and residential facilities. *British Journal of Learning Disabilities, 37*(1), 76-84.
- Griffiths D. M. & Lunskey Y. (2000). Changing attitudes towards the nature of socio-sexual assessment and education for persons with developmental disabilities: a twenty year comparison. *Journal of Developmental Disabilities, 7*, 16-33.
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods, 18*(1), 59-82.

- Guinea, S. M. (2001). Parents with a learning disability and their views on support received: a preliminary study. *Journal of Intellectual Disabilities, 5*(1), 43-56.
- Harris, J. (1994). *Private Lives, Public Spirit: Britain 1870–1914*. Oxford: Oxford University Press.
- Hayman, R. (1990). Presumptions of justice: law, politics and the mentally retarded parent. *Harvard Law Review, 103*, 1201-1271.
- Ho, A. (2004). To be labelled, or not to be labelled: that is the question. *British Journal of Learning Disabilities, 32*, 86-92.
- Holmes, M. (1998). An evaluation of staff attitudes towards the sexual activity of people with learning disabilities. *British Journal of Occupational Therapy, 61*, 111-115.
- IASSID (2008). Parents labelled with Intellectual Disability: Position of the IASSID SIRG on parents and parenting with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 21*, 296-307.
- Jahoda A., Markova I. & Cattermole M. (1989). Stigma and the self concept of people with a mild mental handicap. *Journal of Mental Deficiency Research, 32*, 103-115.
- Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues, 66*(3), 521-534.
- Keltner, B. (1994). 'Home environments of mothers with mental retardation', *Mental Retardation, 32*(2), 123-127.
- Keltner, B., Finn, D., & Shearer, D. (1995). Effects of family intervention on maternal-child interaction for mothers with developmental disabilities. *Family & Community Health, 17*(4), 35-49.

- Keltner, B., Wise, L. & Taylor, G. (1999). Mothers with intellectual limitations and their 2-year-old children's developmental outcomes. *Journal of Intellectual and Developmental Disability, 24*, 45-57.
- Kilcommons, A. M., Withers, P. & Moreno-Lopez, Á. (2012). Do service users with intellectual disabilities want to be involved in the risk management process? A thematic analysis. *Journal of Applied Research in Intellectual Disabilities, 25*, 433-444.
- Krueger, J., & Clement, R. W. (1994). The truly false consensus effect: An ineradicable and egocentric bias in social perception. *Journal of Personality and Social Psychology, 67*(4), 596.
- Levesque, R. (1996). Maintaining children's relations with mentally disabled parents: Recognizing difference and the difference it makes. *Children's Legal Rights Journal, 16*(2), 14-22.
- Leyens, J. P., Yzerbyt, V., & Schadron, G. (1994). *Stereotypes and social cognition*. Thousand Oaks, CA: Sage.
- Lincoln, Y. S., & Guba, E. (1985). *Naturalistic enquiry*. Beverly Hills, CA: Sage.
- Llewellyn, G. & McConnell, D. (2002). Mothers with learning disabilities and their support networks. *Journal of Intellectual Disability Research, 46* (1), 17-34.
- Llewellyn G., McConnell D., Cant R. & Westbrook M. (1999). Support network of mothers with an intellectual disability: an exploratory study. *Journal of Intellectual and Developmental Disability, 24*, 7-26.
- Llewellyn, G., McConnell, D., & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect, 27*(3), 235-251.



- Luckasson, R. et al. (1992). *Mental retardation: Definition, classification, and systems of supports* (9th ed.). Washington, DC: American Association on Mental Retardation.
- MacMillan, D. L., Gresham, F. M., & Bocian, K. (1998). Discrepancy between definitions of learning disabilities and what schools use: An empirical investigation. *Journal of Learning Disabilities, 31*, 314-326.
- Macnicol, J. (1989). Eugenics and the Campaign for Voluntary Sterilization in Britain between the Wars. *Social History of Medicine, 2*(2), 147-169.
- Madill, A., Jordan, A. & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology, 91*, 1-20.
- Marafino, K. (1990). Parental rights of persons with mental retardation. In B. Whitman and P. Accardo (Eds.), *When a Parent is Mentally Retarded* (pp. 163-189). Baltimore: Paul H. Brookes.
- Markowitz, F. E. (2001). Modeling processes in recovery from mental illness: relationships between symptoms, life satisfaction, and self-concept. *Journal of Health and Social Behavior, 64*-79.
- Martin, E., McKenzie, K., Newman, E., Bowden, K., & Morris, P. G. (2011). Care staff intentions to support adults with an intellectual disability to engage in physical activity: An application of the Theory of Planned Behaviour. *Research in developmental disabilities, 32*(6), 2535-2541.
- Mazumdar, P. (1991). *Eugenics, human genetics and human failings: the Eugenics Society, its sources and its critics in Britain*. London: Routledge.

- McCabe, M. P. (1993). Sex education programs for people with mental retardation. *Mental Retardation*, 31, 377-387.
- McConnell, D., Feldman, M., Aunos, M. & Prasad, N. (2010). *Child welfare process and outcomes: Caregiver cognitive impairment*. Edmonton, Alberta: University of Alberta Press.
- McConnell, D. & Llewellyn, G. (2002). Stereotypes, Parents with Intellectual Disability and Child Protection. *Journal of Social Welfare and Family Law*, 24(3), 297-317.
- McConnell, D., Llewellyn, G., & Bye, R. (1997). Providing services for parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability*, 22(1), 5-17.
- McConnell, D., Llewellyn, G., & Ferronato, L. (2000). *Parents with a disability and the NSW Children's Court*. Family Support & Services Project: University of Sydney.
- McConnell, D., Llewellyn, G. & Ferronato, L. (2006). Context contingent decision-making in child protection practice. *International Journal of Social Welfare*, 15, 230-239.
- McConnell, D., Llewellyn, G., Mayes, R., Russo, D. & Honey, A. (2003). Developmental profiles of children born to mothers with intellectual disability. *Journal of Intellectual and Developmental Disability*, 28(2), 122-134.
- McGaw, S. (1996). Services for parents with learning disabilities. *Tizard Learning Disability Review*, 1, 21-8.
- McGaw, S. (1997). Practical support for parents with learning disabilities. In J. O'Hara & A. Sperlinger (Eds.), *Adults with learning disabilities: A*

- practical approach for Health Professionals (pp. 123-138). Chichester: John Wiley and Sons.
- McGaw, S., Scully, T. & Pritchard, C. (2010). Predicting the unpredictable? Identifying high-risk versus low-risk parents with intellectual disabilities. *Child Abuse and Neglect* 34(9), 699-710.
- McGaw, S., Shaw, T., & Beckley, K. (2007). Prevalence of psychopathology across a service population of parents with intellectual disabilities and their children. *Journal of Policy and Practice in Intellectual Disabilities*, 4(1), 11-22.
- McGaw, S., & Sturmey, P. (2006). Assessing parents with learning disabilities: the parental skills model. *Child abuse review*, 3(1), 36-51.
- Mercer, J. R. (1973). *Labeling the mentally retarded*. Berkeley: University of California Press.
- Mickelson, P. (2004). The feeble-minded parent: A study of 90 family cases. *American Journal of Mental Deficiency*, 51, 644-653.
- Mirfin-Veitch, B., Bray, A., Williams, S., Clarkson, J., & Belton, A. (1999). Supporting parents with intellectual disabilities. *New Zealand Journal of Disability Studies*, 6, 60-74.
- Ministry of Justice (2007). *Mental Capacity Act 2005: Code of Practice*. London: Ministry of Justice. Retrieved from [www.justice.gov.uk/guidance/mca-code-of-practice.htm](http://www.justice.gov.uk/guidance/mca-code-of-practice.htm).
- Ministry of Justice (2009). *The Human Rights Act 1998: the Definition of "Public Authority" Government Response to the Joint Committee on Human Rights Ninth Report of Session 2006-07*. London: HMSO.

- Munro, E. (2010). Learning to reduce risk in child protection. *British Journal of Social Work*, 40(4), 1135-1151.
- Myers, F., Ager, A., Kerr, P., & Myles, S. (1998). Outside looking in? Studies of the community integration of people with learning disabilities. *Disability & Society*, 13(3), 389-413.
- Newman, T. (2004). *What works in building resilience*. London: Barnados.
- Newman, T., Day, C. & Warden, S. (2005). *Review of Practitioner Assessments of Good Enough Parenting*. York: Joseph Rowntree Foundation.
- Newton, J., Horner, R., Ard, W., LeBaron, N. & Sappington G. (1994). A conceptual model for improving the social life of individuals with mental retardation. *Mental Retardation*, 32(6), 393-402.
- Nind, M. (2008). Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges. Southampton: University of Southampton, National Centre for Research Methods.
- Nirje, B. (1980). Normalisation Principle and its Human Management Applications. In R.J. Flynn & K.E. Nitsch (Eds.), *Normalization, social integration and human services* (pp. 31-42). Baltimore: University Park Press.
- Owen, F. A., Griffiths, D. M., Feldman, M. A., Sales, C. A., & Richards, D. (2000). Perceptions of acceptable boundaries by persons with developmental disabilities and their care providers. *Journal on Developmental Disabilities*, 7(1), 34-49.
- Parchomiuk, M. (2012). Specialists and sexuality of individuals with disability. *Sexuality and Disability*, 1-13.

- Parenting Research Centre (2010). *Healthy Start: Facts and Stereotypes about children of parents with intellectual disabilities*. Retrieved October 1, 2012, from <http://www.healthystart.net.au/resources>.
- Patton, M. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Perrin, B., & Nirje, B. (1985). Setting the record straight: A critique of some frequent misconceptions of the normalization principle. *Journal of Intellectual and Developmental Disability, 11*(2), 69-74.
- Pixa-Kettner, U. (1998). Parents with intellectual disability in Germany: Results of a nation-wide study. *Journal of Applied Research in Intellectual Disabilities, 11*(4), 355-364.
- Pixa-Kettner, U. (1999). Follow-up study on parenting with intellectual disability in Germany. *Journal of Intellectual & Developmental Disabilities, 24*(1), 75-93.
- Pockney, R. (2006). Friendship or facilitation: people with learning disabilities and their paid carers. *Sociological Research Online, 11*(3).
- Porter, J., & Lacey, P. (2005). *Researching learning difficulties*. London: Sage
- Reder, P., Duncan, S. & Lucey, C. (2003). *Studies in the Assessment of Parenting*. London: Routledge.
- Reilly, P. (1991). *The surgical solution: A history of involuntary sterilization in the United States*. Baltimore: Johns Hopkins University Press.
- Rice, H. K. (1968). Operant behavior in vegetative patients III: methodological considerations. *Psychological Record, 18*, 297-302.

- Ryan, G. W., & Bernard, H. R. (2000). Data management and analysis methods. In NK Denzin & YS Lincoln (Eds.), *Handbook of qualitative research* (2nd Ed., pp. 769-802). Thousand Oaks, CA: Sage.
- Sayer, A. (2000). *Realism and social science*. Thousand Oaks, CA: Sage.
- Scally, B. (1973). Marriage and mental handicap: some observations in Northern Ireland. In de la Cruz, F. & LaVeck, G. (Eds.), *Human Sexuality and the Mentally Retarded*. New York: Brunner/Mazel.
- Scheff, T.J. (1966). *Being Mentally Ill: A sociological theory*. New York: Aldine.
- Scott, J. K., Wishart, J. G., & Bowyer, D. J. (2006). Do current consent and confidentiality requirements impede or enhance research with children with learning disabilities? *Disability & Society*, 21(3), 273-287.
- Sellars, C. (2011). *Risk assessment in people with learning disabilities*. Chichester, UK: Wiley.
- Shaw, C. H. & Wright, C. H. (1960). 'The married mental defective: a follow-up study', *The Lancet*, 30, 273-274.
- Sheehan, R., & Levine, G. (2005). Parents with Mental Illness: Decision-making in Australian Children's Court Cases Involving Parents with Mental Health Problems. *Journal of Social Welfare and Family Law*, 27(1), 17-30.
- Sheerin, F. (1998). Parents with learning disabilities: A review of the literature. *Journal of Advanced Nursing*, 28, 126-133.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54.

- Smith, J. A., & Osborn, M. (2003). Interpretative phenomenological analysis. *Qualitative psychology: A practical guide to research methods*, 51-80.
- Smith, J. D. & Wehmeyer, L. M. (2012). *Good Blood, Bad Blood: Science, Nature, and the Myth of the Kallikaks*. Washington, DC : AAIDD.
- Sinason, V. (1992). *Mental handicap and the human condition*. London: Free Association Books.
- Soloway, R. A. (1995). *Demography and Degeneration*. Chapel Hill: University of North Carolina Press.
- Stalker, K. (1998). Some ethical and methodological issues in research with people with learning difficulties. *Disability & Society*, 13(1), 5-19.
- Swango-Wilson, A. (2008). Caregiver perception of sexual behaviors of individuals with intellectual disabilities. *Sexuality and Disability*, 26(2), 75-81.
- Tarleton, B., Ward, L. & Howarth, J. (2006). *Finding the right support. A review of issues and positive practice in supporting parents with learning difficulties and their children*. London: Baring Foundation.
- Taylor, C. G., Norman, D. K., Murphy, J. M., Jellinek, M., Quinn, D., Poitras, F. G., & Goshko, M. (1991). Diagnosed intellectual and emotional impairment among parents who seriously mistreat their children: Prevalence, type, and outcome in a court sample. *Child abuse & neglect*, 15(4), 389-401.
- Terkel, S. (1968). *Division street: America*. London: Allen Lane.

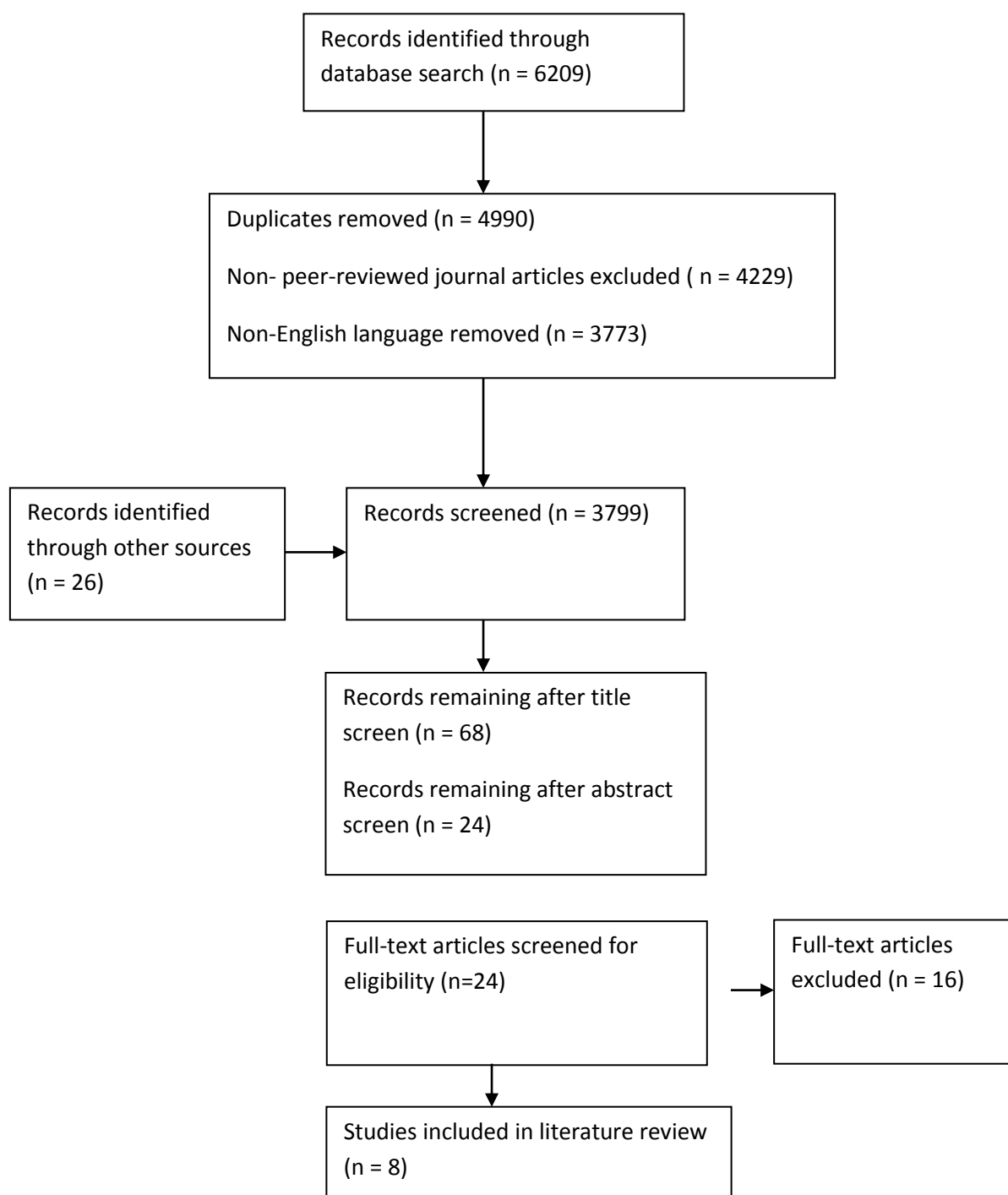
- Thomas, A. (2000). Stability of Tringo's hierarchy of preference toward disability groups: 30 years later. *Psychological Reports*, 86(3), 1155-1156.
- Thomson, M. (1998). *The Problem of Mental Deficiency: Eugenics, Democracy and Social Policy in Britain c.1870-1959*. Oxford: Clarendon.
- Tucker, B. & Johnson, O. (1989). Competence promoting vs. competence inhibiting social support for mentally retarded mothers. *Human Organization*, 48, 95-107.
- Tuckett, A. G. (2004). Part 1: Qualitative research sampling-the very real complexities. *Nurse Researcher*, 12(1), 47-61.
- Tymchuk, A. J., & Andron, L. (1990). Mothers with mental retardation who do or do not abuse or neglect their children. *Child Abuse & Neglect*, 14(3), 313-323.
- Tymchuk, A. J., & Feldman, M.A. (1991). Parents with mental retardation and their children: A review of research relevant to professional practice. *Canadian Psychology/Psychologie Canadienne*, 32, 486-496.
- Wade, C., Llewellyn, G. & Matthews, J. (2008). Review of parent training interventions for parents with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 21, 351-366.
- Wade, C. M., Mildon, R. L. & Matthews, J. M. (2007). Service delivery to parents with an intellectual disability: Family-centred or professionally centred? *Journal of Applied Research in Intellectual Disabilities*, 20, 87-98.
- Walmsley, J. (2001). Normalisation, emancipatory research and learning disability. *Disability and Society*, 16, (2), 187-205.



- Wechsler, D. (2008a). *Wechsler Adult Intelligence Scale—Fourth Edition*. San Antonio, TX: Pearson.
- Werner, S., Corrigan, P., Ditchman, N., & Sokol, K. (2012). Stigma and intellectual disability: A review of measures and future directions. *Research in Developmental Disabilities, 33*, 748-765.
- Whitcraft, C. & Jones, J. P. (1974). A survey of attitudes about sterilization of retardates. *Mental Retardation, 12*, 30-33.
- Wolfe, P. (1997). The influence of personal values on issues of sexuality and disability. *Sexuality and Disability, 15*, 69-90.
- Woodcock, J. (2003). The social work assessment of parenting: an exploration. *British Journal of Social Work, 33*, 87-106.
- Wood Report (1929). *Report of the Mental Deficiency Committee*. London: HMSO.
- White, A. (1901). *Efficiency and Empire*. London: Methuen & Co.. Retrieved from <http://www.archive.org/details/efficiencyandem00whitgoog>.
- Whittemore, R., Chase, S. K., & Mandle, C. L. (2001). Validity in qualitative research. *Qualitative health research, 11*(4), 522-537.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and health, 15*(2), 215-228.

## **Appendices**

Appendix A - PRISMA diagram for selection of papers



## Appendix B – Newcastle-Ottawa Scale adapted for cross-sectional studies

### **Selection:** (Maximum 5 stars)

#### 1) Representativeness of the sample:

- a) Truly representative of the average in the target population. \* (all subjects or random sampling)
- b) Somewhat representative of the average in the target population. \* (non-random sampling)
- c) Selected group of users.
- d) No description of the sampling strategy.

#### 2) Sample size:

- a) Justified and satisfactory. \*
- b) Not justified.

#### 3) Non-respondents:

- a) Comparability between respondents and non-respondents characteristics is established, and the response rate is satisfactory. \*
- b) The response rate is unsatisfactory, or the comparability between respondents and non-respondents is unsatisfactory.
- c) No description of the response rate or the characteristics of the responders and the non-responders.

#### 4) Ascertainment of the exposure (risk factor):

- a) Validated measurement tool. \*\*
- b) Non-validated measurement tool, but the tool is available or described.\*
- c) No description of the measurement tool.

### **Comparability:** (Maximum 2 stars)

#### 1) The subjects in different outcome groups are comparable, based on the study design or analysis. Confounding factors are controlled.

- a) The study controls for the most important factor (select one). \*
- b) The study control for any additional factor. \*

### **Outcome:** (Maximum 3 stars)

#### 1) Assessment of the outcome:

- a) Independent blind assessment. \*\*
- b) Record linkage. \*\*
- c) Self report. \*
- d) No description.

#### 2) Statistical test:

- a) The statistical test used to analyze the data is clearly described and appropriate, and the measurement of the association is presented, including confidence intervals and the probability level (p value). \*
- b) The statistical test is not appropriate, not described or incomplete.



## **Professional Information Sheet**

Research title: Parents with Learning Disabilities:  
Assumptions made by mental health professionals about their right and ability to be a parent.

### **1. What is the purpose of this research?**

This research is designed to look at whether parents with learning disabilities believe there to be assumptions made about their ability and right to be a parent by mental health professionals. This research will make up the thesis component of a Doctorate in Clinical Psychology. After the research is completed, generalised findings will be presented to your teams to enhance awareness of some of the issues raised.

### **2. Why have I been approached?**

You have been approached as you are a professional who may be aware of a parent who has been identified as having learning disabilities on your caseload, who may be appropriate to participate in this research. It is felt that you are an appropriate person to identify whether or not a service user is a suitable candidate for participation within this research.

### **3. Do I have to participate?**

There is no obligation to take any part in the identification of potential participants. Your decision whether to contribute to this research is entirely voluntary.

### **4. What will my participation involve?**

If you identify any suitable participants, based upon your clinical judgement as well as the inclusion/ exclusion criteria listed below, you will be asked to introduce the research to the potential participants, using the 'Participant Information Sheet'. If the potential participant expresses an initial interest in taking part in the research, you will be asked to request their permission to pass their contact details to the Chief Investigator, who will arrange to discuss their participation in more detail. Their decision whether or not to participate is completely autonomous.

### **5. What will the research involve?**

If parents with learning disabilities agree to be contacted by the Chief Investigator, a meeting will be arranged to discuss the research in more detail and to gain written informed consent. A further appointment will then be made for an interview, where they will be asked to discuss topics around their experience of parenting within the healthcare and judicial systems. This will last up to a maximum of two hours.

## **6. Who can take part?**

The research is open to any individuals over the age of 18 who have been identified as having a learning disability and who have undergone any form of parenting assessment. The research is appropriate for mothers or fathers, as long as they currently have at least one child under the age of 18 living at home. It will be possible for both parents of the same child to be included in the study, however they would be interviewed separately and considered as separate participants. Given the nature of the research, it is necessary that the individual has reasonable communication skills in the English language and is able to provide informed consent. Due to the sensitivity of the subject area, potential participants will be excluded if they are currently involved in child protection proceedings.

## **7. What are the possible risks or benefits of taking part?**

No adverse effects are anticipated for potential participants. Although it is a potentially sensitive area for discussion, this will be made clear to participants in the information sheet. While every effort will be made to provide support during the interview by the Chief Investigator, participants will be referred to an appropriate member of their care team if further support is required. It will also be emphasised that participation in the research will have no impact on the services they receive. Upon completion of the research, participants will receive a general report of findings and the results will be shared with the wider clinical teams. This research may benefit learning disability services in the longer-term as it could highlight a pattern of assumptions as perceived by parents with learning disabilities about their ability and right to be a parent, which could be impacting on their engagement with services and with professionals. Findings from the research will also be submitted for publication in a peer-reviewed journal which could benefit the wider clinical community.

## **8. What will happen to the results of the research study?**

The results will be written up and presented as part of a Clinical Psychology Doctoral thesis. Patients will receive a general summary of research findings in the form of brief written feedback and the clinical team will receive a brief presentation of the research findings. It may also be presented at academic conferences and submitted for publication in peer-reviewed academic journals. It is possible that direct quotes from the interviews will be used in the research, however all quotes will be anonymised.

## **8. Who is managing and funding the research?**

The research is managed by Joanna Rose, who is a doctoral student currently enrolled in the Trent Doctorate in Clinical Psychology, under the supervision of Dr Rachel Sabin-Farrell. The project is funded by the University of Lincoln.

## **9. Who has reviewed the study?**

This research has been reviewed through the University Peer Review process and has been approved by the Chair of Lincoln University Ethics committee, Dr Emile van der Zee (Tel: 01522 886140; Email: [evanderzee@lincoln.ac.uk](mailto:evanderzee@lincoln.ac.uk)). The study has also been reviewed by the Leicester Research Ethics Committee.

If you require any further information, please do not hesitate to contact the Chief Investigator or Research Supervisor.

### **Contacts for further information:**

#### Chief Investigator

Joanna Rose  
Doctorate Course in Clinical Psychology  
Court 11, Satellite Building 8  
University of Lincoln  
Brayford Pool  
Lincoln, LN6 7TS  
01522 886029  
[10197388@students.lincoln.ac.uk](mailto:10197388@students.lincoln.ac.uk)

#### Research Supervisor

Rachel Sabin-Farrell  
Senior Academic Tutor  
Trent Doctorate in Clinical Psychology  
I-WHO, University of Nottingham  
Jubilee Campus, Wollaton Road  
Nottingham, NG8 1BB.  
0115 8466734  
[rachel.sabin-farrell@nottingham.ac.uk](mailto:rachel.sabin-farrell@nottingham.ac.uk)

**Thank you for your time.**

**Topic 1: Background information**

Name

Age

Children (number and ages)

Partner (length of relationship)

Living arrangements

Education

Mental Health

Physical Health

Employment

Child's mental/ physical health

Involvement with Mental Health Services

Support received

**Topic 2: Decision to be a parent**

Can you remember when you first thought about having a baby?

- Was it before you found out you/ your partner were pregnant

Did you talk to anybody about it?

- Partner/ family/ friends/ professionals

Did they say it was a good idea or a bad idea?

- How did you feel about what they said?

Why did you want to have a baby?

**Topic 3: Expectation of being a parent**

What did you think it would be like to have a baby?

- **Prompt:** exciting/ scary/ difficult/ brilliant

Did the things people said about you having a baby change what you thought?

Did you think you would do a good job of being a mum/ dad?



Were there times you thought about not having a baby?

#### **Topic 4: Experience of being a parent**

What is it like to be a mum/ dad?

Is it the same or different to how you thought it would be?

Are there things you find difficult?

Are there things you find easy?

#### **Topic 5: Experience of child protection/ safeguarding (if applicable)**

Were there people who were worried about whether you could look after your child?

- Child protection/ court cases/ safeguarding

What was it like for you when those things were going on?

- Did it feel like people were trying to help?
- Did you want to talk to the professionals who were involved?

What happened in the end?

#### **Topic 6: Expectation of assumptions**

When you decided to have a baby, did you think what other people might think?

- Family/ professionals/ partner

Did that change how you thought about it?

Did you think professionals would treat you the same as everybody else?

Did you think they might want to take the baby away?

Did you think professionals might make guesses about what you would be like as a mum/ dad?

Did you make guesses about what you might be like as a mum/ dad?

Why did you think these things?

Did thinking about these guesses change how you thought about being a mum?

- Did you not want to talk to people about it?
- Did you get more worried that you couldn't do it?
- Did you worry more about asking people for help?
- 

#### **Topic 7: Experience of assumptions**

Which different professionals have worked with you?

How have you found working with professionals?

What do you think they think about you?

- Whether you are a good mum/ dad
- Whether you should be a mum/ dad

Do you think they want/ wanted to help you keep your child at home

Are there differences in the way different professionals have treated you?

Have any of the professionals ever said anything to you about this?

How have professionals acted towards you since you decided to have a baby?

Does it feel like professionals treat you the same way as everybody else?

Do you feel like having a learning disability made it more/ less likely that you could keep your baby?

Has the way professionals have treated you affected you?

- Your confidence
- The way you see yourself
- Your relationships
- How much you want to engage with services
- 

### **Topic 8: Most/ least helpful experiences**

What has been the most helpful thing about how professionals have worked with you?

What has been the least helpful thing about how professionals have worked with you?

Have there been any other ways professionals have been helpful?

Have there been any other ways professionals have been unhelpful?

Do the different professionals you work with talk to each other?

Do you feel professionals have provided you with the support you need to be a good mum/ dad?

Have you attended any groups/ courses to help you with being a good mum/ dad?

### **Topic 9: Future Plans**

Overall, what do you think is good about the way professionals work with people with learning disabilities who want to become or are parents?

Overall, what do you think could be improved about the way professionals work with people with learning disabilities who what to become or are parents?

Do you think you might have more children in the future?

Do you think you would continue engaging with services if you have more children in the future?

## **Appendix E – Ethical Approval**

Leicester Research Ethics Committee Approval



**Health Research Authority**

**NRES Committee East Midlands - Leicester**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839425  
Facsimile: 0115 8839294

18 January 2012

Miss Joanna Rose  
Trainee Clinical Psychologist  
Lincolnshire Partnership Foundation Trust  
University of Lincoln,  
Health, Life and Social Sciences, 1st Floor, Bridge House  
Brayford Pool, Lincoln  
LN6 7TS

Dear Miss Rose,

**Study Title:** Parents with Learning Disabilities: their expectations  
and experience of the assumptions made by  
professionals about their ability and right to be a parent  
**REC reference:** 12/EM/0008

The Research Ethics Committee reviewed the above application at the meeting held on 06 January 2012.

**Documents reviewed**

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter		08 December 2011
Evidence of insurance or indemnity		22 July 2011
GP/Consultant Information Sheets	1.1	07 November 2011
Interview Schedules/Topic Guides	1.1	07 November 2011
Investigator CV		06 December 2011
Other: CV Academic Supervisor		01 December 2011
Participant Consent Form	1.1	07 November 2011
Participant Information Sheet	1.1	07 November 2011
Protocol	1.2	28 November 2011
REC application	92288/273697/1/884	08 December 2011

**Provisional opinion**

- The committee noted that participants are going to be identified by a professional whose attitudes may be amongst those who are being explored in the interviews.
- The committee raised concerns as to whether the interviews can be terminated if distress is caused.

'professional' should be amended to 'professionals'.

e) Under the heading 'What is the purpose of this research?' The word 'proponent' should be corrected with 'component'

2. The following amendments should be made to the LD Participant Information Sheet:

a) The title should be corrected to read 'Information sheet for parent with learning difficulties'

b) Under the heading 'Who has reviewed the study' should be included and should list the Leicester Research Ethics Committee

c) It should be made explicit how long tapes will be kept for

d) Under the heading 'What will I be asked to do?' The first sentence should be amended to read 'I would like to have a look at your notes to find out about what sort of things you are good at and what you find a bit more difficult.'

e) Under the heading 'What will happen next?' the first sentence should read 'If you say YES to taking part in the study, I will ask you to sign a consent form.'

f) It is assumed that the children will remain living at home, it is not anticipated that if something is revealed this may have an impact on who the child lives with in the future, this should be made clear.

3. The following amendment should be made to the Consent Form:

a) The title should be amended to read 'Consent Form for Parent with Learning Difficulties'

4. An invitation should be submitted to be reviewed

**If you would find it helpful to discuss any of the matters raised above or seek further clarification from the committee co-ordinator, you are welcome to contact Miss Jessica Parfremont on 01158839425.**

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 17 May 2012.

### **Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet.

A committee member is involved in the same school but has had no involvement in the design of the study. The committee agreed the member could remain in the meeting room and take a full part in the review

### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely

PP J. Parfremment

**Dr Carl Edwards**  
**Chair**

Email: [jessica.parfremment@nottspct.nhs.uk](mailto:jessica.parfremment@nottspct.nhs.uk)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.*

*Copy to: Sponsor - Sara Owen*  
*R&D Contact – LPT*



## Health Research Authority

### NRES Committee East Midlands - Leicester

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839425  
Facsimile: 0115 8839294

08 March 2012

Miss Joanna Rose  
Trainee Clinical Psychologist  
Lincolnshire Partnership Foundation Trust  
University of Lincoln,  
Health, Life and Social Sciences, 1st Floor, Bridge House  
Brayford Pool, Lincoln  
LN6 7TS

Dear Miss Rose,

**Study title:** Parents with Learning Disabilities: their expectations  
and experience of the assumptions made by  
professionals about their ability and right to be a parent  
**REC reference:** 12/EM/0008

Thank you for your letter of 06 February 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

##### Non-NHS sites

#### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*



Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

1. The committee suggest that the committee members amended version of the Participant Information Sheet and Invitation is to be used

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		08 December 2011
Evidence of insurance or indemnity		22 July 2011
GP/Consultant Information Sheets	1.1	07 November 2011
Interview Schedules/Topic Guides	1.1	07 November 2011
Investigator CV		06 December 2011
Letter of invitation to participant	1	24 January 2012
Other: CV Academic Supervisor		01 December 2011
Participant Consent Form: Parent with Learning Disabilities	1.2	24 January 2012
Participant Information Sheet: Professional	1.2	24 January 2012
Participant Information Sheet: Parent with Learning Disabilities	1.2	24 January 2012
Protocol	1.2	28 November 2011
REC application	1	08 December 2011
Response to Request for Further Information		06 February 2012

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

## **After ethical review**

### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**12/EM/0008**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr Carl Edwards**  
**Chair**

Email: [jessica.parfremment@nottspct.nhs.uk](mailto:jessica.parfremment@nottspct.nhs.uk)

Enclosures: "After ethical review – guidance for researchers"  
Copy to: Sponsor - Sara Owen

*R&D Contact - Mrs Dianne Tetley*

**NRES Committee East Midlands - Leicester**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

Telephone: 0115 8839425  
Facsimile: 0115 8839294

09 March 2012

Miss Joanna Rose  
Trainee Clinical Psychologist  
Lincolnshire Partnership Foundation Trust  
University of Lincoln,  
Health, Life and Social Sciences, 1st Floor, Bridge House  
Brayford Pool, Lincoln  
LN6 7TS

Dear Miss Rose,

**Full title of study:**           **Parents with Learning Disabilities: their expectations and experience of the assumptions made by professionals about their ability and right to be a parent**

**REC reference number:**   **12/EM/0008**

Thank you for your email of 08 March 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 09 March 2012. Please note these documents are for information only and have not been reviewed by the committee.

**Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letter of Invitation to participant		
1.1	08 March 2012	
Participant Information Sheet	1.2	24 January 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**12/EM/0008**

**Please quote this number on all  
correspondence**

Yours sincerely

**Miss Jessica Parfremment  
Committee Co-ordinator**

E-mail: [jessica.parfremment@nottspct.nhs.uk](mailto:jessica.parfremment@nottspct.nhs.uk)

*Copy to: Sponsor - Sally Owen*

*R&D Contact - Mrs Dianne Tetley*

University of Lincoln Ethical Approval



Lincoln, 9-3-2012

Dear Joanna Rose,

The Ethics Committee of the School of Psychology would like to inform you that your project on "What attitudes have parents with learning disabilities experienced from professionals involved in their care and what impact does this have on their parenting ability?" is:

☒ approved, including the minor changes you communicated to me on 9-3-2012, as a result of your IRAS application.

☐ approved subject to the following conditions:

☐ invited for resubmission, taking into account the following issues:

☐ is rejected. An appeal can be made to the Faculty Ethics Committee against this decision ([cawalker@lincoln.ac.uk](mailto:cawalker@lincoln.ac.uk)).

☐ is referred to the Faculty Ethics Committee, or the University Ethics Committee. You will automatically be contacted by the chair of the Faculty Ethics Committee about further procedures.

Yours sincerely,



Emile van der Zee, PhD

Chair of the Ethics Committee  
School of Psychology  
University of Lincoln  
Brayford Campus  
Lincoln LN6 7TS  
United Kingdom  
telephone: +44 (0)1522 886140  
fax: +44 (0)1522 886026  
e-mail: [evanderzee@lincoln.ac.uk](mailto:evanderzee@lincoln.ac.uk)  
<http://www.lincoln.ac.uk/psychology/staff/683.asp>

Norfolk Community Health and Care NHS Trust R&D Approval

Norfolk Community   
Health and Care  
NHS Trust

Ref: 2012LD01

**Miss Joanna Rose**  
Health, Life and Social Sciences  
University of Lincoln  
1<sup>st</sup> Floor, Bridge House  
Brayford Pool  
Lincoln  
LN6 7TS

**Research & Development**  
NHS Norfolk  
Lakeside 400  
Old Chapel Way  
Broadland Business Park  
Thorpe St Andrew  
Norwich  
NR7 0WG

Tel: 01603 257283  
Fax: 01603 257292  
E-mail: [paul.mills@norfolk.nhs.uk](mailto:paul.mills@norfolk.nhs.uk)  
[www.norfolk.nhs.uk/research](http://www.norfolk.nhs.uk/research)

27 March 2012

Dear Miss Rose,

**Re: 2012LD01. Parents with Learning Disabilities: their expectations and experience of the assumptions made by professionals about their ability and right to be a parent.**

**REC Number:** 12/EM/0008

**Chief Investigator:** Miss Joanna Rose, University of Lincoln

**Sponsor:** University of Lincoln

Further to your submission of the above project to the R&D office at NHS Norfolk your project has now been reviewed and all the mandatory research governance checks for Participant Identification Centres<sup>1</sup> (PICs) have now been satisfied. I am therefore pleased to inform you on behalf of **Norfolk Community Health & Care** that that agreement was granted on **26<sup>th</sup> March 2012** for the following Participant Identification Centres to refer patients for this study:

- Learning Disabilities, West Team – Norfolk Community Health & Care NHS Trust

Please note that NHS Permission is granted on the basis of the information supplied in the research governance submission, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

Please note that the PCT does not indemnify the research site, the host organisation or the participants in relation to the conduct or management of the research; the responsibility for indemnity arrangements rests with the study Sponsor.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework. I have enclosed two copies of the Standard Terms and Conditions of Approval for PICs. Please sign and return one copy to the R&D office at the above address. Failure to return the standard terms and conditions may result in agreement being revoked.

<sup>1</sup> Where potential participants will be identified through NHS organisations other than the research sites themselves, these organisations are termed "Participant Identification Centres" (PIC) IRAS Question Specific Guidance - Part C Version 2.2 dated April 2009

**Please note, under the agreed standard terms and conditions you must inform the R&D Office at NHS Norfolk of any proposed changes to this study, whether minor or substantial, and to keep the office updated on progress, particularly the contribution of the PICs in Norfolk & Suffolk to screening and recruitment.**

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer, at the above address. Please note, the reference number for this study is **2012LD01** and this should be quoted on all correspondence.

The following documents were reviewed:

Letter of Favourable Opinion from NRES Committee East Midlands – Leicester, dated 8<sup>th</sup> March 2012

- Evidence of Insurance/Indemnity, 22<sup>nd</sup> July 2011
- Interview Schedule/Topic Guide, Version 1.1, 7<sup>th</sup> November 2011
- Investigator CV – Joanna Rose
- Investigator CV – Dr Rachel Sabin-Farrell
- Participant Consent Form, Version 1.2, 24<sup>th</sup> January 2012
- Participant Information Sheet – Professionals, Version 1.2, 24<sup>th</sup> January 2012
- Protocol, Version 1.2, 28<sup>th</sup> November 2011

Letter of Acknowledgement of Compliance with Conditions from NRES Committee East Midlands – Leicester, dated 9<sup>th</sup> March 2012

- Participant Invitation Letter, Version 1.1, 8<sup>th</sup> March 2012
- Participant Information Sheet, Version 1.2, 24<sup>th</sup> January

Other Documents Reviewed

- Signed NHS R&D Form, Lock Code 92288/282276/14/919

Yours sincerely



Dr Augustine Pereira

**Consultant in Public Health Medicine, and Research & Development Lead  
NHS Norfolk & Waveney**

*Signed on behalf on Norfolk Community Health & Care NHS Trust*

cc: Sara Owen, University of Lincoln, Sponsor Representative  
Dr Rachel Sabin Farrell, University of Nottingham, Academic Supervisor  
Anne-Marie Mensink, Norfolk Community Health & Care NHS Trust, Local Collaborator  
File

Ref: 2012LD01

**Miss Joanna Rose**  
Health, Life and Social Sciences  
University of Lincoln  
1<sup>st</sup> Floor, Bridge House  
Brayford Pool  
Lincoln  
LN6 7TS

**Research & Development**

NHS Norfolk  
Lakeside 400  
Old Chapel Way  
Broadland Business Park  
Thorpe St Andrew  
Norwich  
NR7 0WG

Tel: 01603 257283  
Fax: 01603 257292  
E-mail: [paul.mills@norfolk.nhs.uk](mailto:paul.mills@norfolk.nhs.uk)  
[www.norfolk.nhs.uk/research](http://www.norfolk.nhs.uk/research)

20 April 2012

Dear Miss Rose,

**Re: 2012LD01. Parents with Learning Disabilities: their expectations and experience of the assumptions made by professionals about their ability and right to be a parent.**

**REC Number:** 12/EM/0008

**Chief Investigator:** Miss Joanna Rose, University of Lincoln

**Sponsor:** University of Lincoln

NHS permission was granted on 26<sup>th</sup> March 2012 for the West Learning Disabilities Team to act as a Participant Identification Centre<sup>1</sup> (PIC) and refer patients to your study. Following this approval you requested that this permission be extended to other Community Learning Disabilities Teams within Norfolk Community Health & Care NHS Trust to help with recruitment.

Further to this request I am pleased to inform you on behalf of **Norfolk Community Health & Care** that agreement was granted on **20<sup>th</sup> April 2012** to extend NHS Permission for the following Community Learning Disabilities Teams to act as Participant Identification Centres for your study:

- City Learning Disabilities Team, Norfolk Community Health & Care NHS Trust
- East Learning Disabilities Team, Norfolk Community Health & Care NHS Trust
- Northern Learning Disabilities Team, Norfolk Community Health & Care NHS Trust
- Southern Learning Disabilities Team, Norfolk Community Health & Care NHS Trust

Please note that NHS Permission is granted on the basis of the information supplied in the research governance submission, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

---

<sup>1</sup> Where potential participants will be identified through NHS organisations other than the research sites themselves, these organisations are termed "Participant Identification Centres" (PIC) IRAS Question Specific Guidance - Part C Version 2.2 dated April 2009



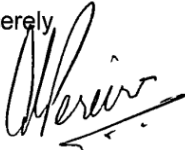
Please note that the PCT does not indemnify the research site, the host organisation or the participants in relation to the conduct or management of the research; the responsibility for indemnity arrangements rests with the study Sponsor.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework. I have enclosed two copies of the Standard Terms and Conditions of Approval for PICs. Please sign and return one copy to the R&D office at the above address. Failure to return the standard terms and conditions may result in agreement being revoked.

**Please note, under the agreed standard terms and conditions you must inform the R&D Office at NHS Norfolk of any proposed changes to this study, whether minor or substantial, and to keep the office updated on progress, particularly the contribution of the PICs in Norfolk & Suffolk to screening and recruitment.**

If you have any queries regarding this or any other project please contact Paul Mills, R&D Officer, at the above address. Please note, the reference number for this study is **2012LD01** and this should be quoted on all correspondence.

Yours sincerely,



Dr Augustine Pereira  
**Consultant in Public Health Medicine, and Research & Development Lead**  
**NHS Norfolk & Waveney**  
*Signed on behalf on Norfolk Community Health & Care NHS Trust*

cc: Sara Owen, University of Lincoln, Sponsor Representative  
Dr Rachel Sabin Farrell, University of Nottingham, Academic Supervisor  
Anne-Marie Mensink, Norfolk Community Health & Care NHS Trust, Local Collaborator  
File

Nottinghamshire Healthcare NHS Trust R & D Approval

positive

Nottinghamshire Healthcare 

NHS Trust

Positive about mental health and learning disability

Research Management and Governance

Institute of Mental Health

2<sup>nd</sup> Floor, Duncan MacMillan House

Porchester Road

Nottingham

Tel: 0115 969 1300

Local Ref: LD/24/04/12

Rec ID: 12/EM/0008

Date: 24<sup>th</sup> April 2012

Miss Joanne Rose  
Lincolnshire Partnership Foundation Trust  
University of Lincoln  
Health, Life and Social Sciences  
1<sup>st</sup> Floor, Bridge House  
Brayford Pool  
Lincoln  
LN6 7TS

Dear Miss Rose

I am writing to confirm that NHS permission for research has been granted for the following study.

**Title: Parents with Learning Disabilities:** Assumptions made by mental health professionals about their ability and right to be a parent

**Sites/ services that have been given NHS permission:** Nottinghamshire Healthcare NHS Trust – Learning Disabilities Service

**NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The following documents were reviewed:**

Document	Version Number
GP/ consultation information sheets	1.1 07/11/2011
Interview schedule	1.1 07/11/2011
Protocol	1.2 28/11/2011
Professional Information Sheet	1.2 24/01/2012
Consent form for parents with LD	1.2 24/01/2012
Invitation letter	1.1 08/03/2012

**Start Date:** 24/04/2012 **End Date:** 31/12/2012

**Study Outline:**

The aim of the study is to explore the experiences parents with learning disabilities have of assumptions made by professionals with regards to their right and ability to be a parent. Semi structured interviews will be undertaken to elicit the impact these expectations and experiences have on parents with LD.

Scores from IQ tests will be obtained from their medical records subject to consent being given; this will be supervised by Dr Bradley.

An NHS to NHS Letter of Access has been issued to Miss Joanna Rose

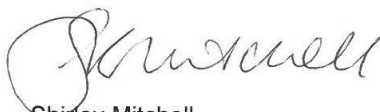
Please note that Nottingham Healthcare NHS Trust is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research and requesting the completion of a brief progress report every 6 months.

You can now proceed with your study in accordance with the agreed protocol. Please keep this letter with you during the course of your research to confirm that you have Directorate and RMG Department approval, to gain access to the areas where your research is taking place.

If you or others have concerns please contact the RMG department by email to [emma.pearson@nottshc.nhs.uk](mailto:emma.pearson@nottshc.nhs.uk)

We wish you well with your work.

Yours sincerely



Shirley Mitchell  
Head of Research Management and Governance

Cc: Dr Rachel Bradley  
Sponsor: Sara Owen  
Academic Supervisor: Dr Rachel Sabin-Farrell

**Conditions of Trust approval are as follows.**

1. All members of the research team should familiarise themselves with all relevant policies and procedures, including the Trust policy GG/CG/04 – staff conducting, hosting or collaborating in research (note, currently being revised).
2. The Chief Investigator, and all other members of the research team, should comply with any regulations applicable to the study, including, but not limited to: The NHS Research Governance Framework for Health and Social Care (2005), The Declaration of Helsinki (2000), The UK Medicines for Human Use (Clinical Trials) Regulations (2004), ICH Good Clinical Practice guidelines (1997), The Human Tissue Act (2004), The Data Protection Act (1998), The Mental Capacity Act (2005).
3. The Chief Investigator should ensure that all members of the research team are suitably qualified and experienced, and adequately supervised. This should include training in informed consent procedures and GCP, where necessary.
4. Research governance should be notified within the same timeframe of notifying REC of any major changes to the study, which may include changes to the team, requiring honorary contracts or letters of access to be issued, changes to timescales or changes in procedures.
  - a. Any changes in the protocol or documentation should be approved by the ethics committee and research governance.
5. Care professionals should be informed of their patients' participation in the research.
6. The protocol should be adhered to; any deviations should be notified to research governance.
7. Suitable arrangements for archiving should be made in accordance with the guidelines of the sponsor, and research governance should be kept informed of any changes or failures in archiving arrangements, including failures in safe preservation of electronic data. Failure to report such losses will result in disciplinary investigation of Trust staff, and a disciplinary enquiry of external researchers, which could result in the rescinding of rights to carry research in the Trust.

Lincolnshire Partnership Foundation Trust R&D Approval

Lincolnshire Partnership 

NHS Foundation Trust

Ref: 12/EM/0008  
Date: 19<sup>th</sup> March 2012

Research and Effectiveness Team  
Trust Headquarters  
Unit 9, The Point  
Lions Way  
SLEAFORD  
Lincolnshire  
NG34 8GG

Miss Joanna Rose  
Trainee Clinical Psychologist  
University of Lincoln  
Health, Life and Social Sciences  
1<sup>st</sup> Floor Bridge House  
Brayford Pool  
Lincoln  
LN6 7TS

Tel: 01529 222206  
Fax: 01529 222226

Dear Joanna Rose

**Study title: Parents with Learning Disabilities: their expectations and experience of the assumptions made by professionals about their ability and right to be a parent.**

**Chief investigator name: Dr Rachel Sabin-Farrell**  
**Sponsor name: Lincoln University**  
**REC number: 12/EM/0008**  
**Date of permission: 19<sup>th</sup> March 2012**

List of all site(s) for which NHS permission for research is given: Lincolnshire Partnership NHS Foundation Trust

NHS permission for the above research has been granted by Lincolnshire Partnership NHS Foundation Trust on the basis described in the application form, protocol and supporting documentation.

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP and NHS Trust policies and procedures (available at <http://www.lpt.nhs.uk/>).

Permission is only granted for the activities for which a favourable opinion has been given by the REC [and which have been authorised by the MHRA]

The research sponsor or the Chief Investigator, or the local Principal Investigator at a research site, may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety.

The Research and Effectiveness office should be notified, at the address above, that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The Research and Effectiveness Office should be notified within the same time frame of notifying the REC and any other regulatory bodies.



Any research carried out by a Trust employee with the knowledge and permission of the employing organisation will be subject to NHS indemnity. NHS indemnity provides indemnity against clinical risk arising from negligence through the Clinical Negligence Scheme for Trusts (CNST). Further details can be found at Research in the NHS: Indemnity arrangements (Department of Health 2005).

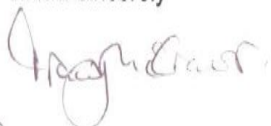
All amendments (including changes to the local research team) need to be submitted in accordance with guidance in IRAS.

Please inform the Research and Effectiveness department of any changes to study status.

Please note that the NHS organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research.

We are pleased to inform you that you may now commence your research. Please retain this letter to verify that you have Trust permission to proceed. We wish you every success with your work.

Yours sincerely



**Dianne Tetley**  
**Assistant Director Research and Effectiveness**  
**Lincolnshire Partnership NHS Foundation Trust**

Cc Chief Investigator Dr Rachel Sabin-Farrell – University of Nottingham

Enc: Data Protection Guidance on the transportation of personal identifiable data



**Trent Doctorate in Clinical  
Psychology**



DClinPsy  
Faculty of HLSS  
University of Lincoln  
1st Floor, Bridge House  
Brayford Pool  
Lincoln  
LN6 7TS

## Invitation to take part in research

My name is Joanna Rose. I am a Trainee Clinical Psychologist studying for a qualification at the University of Lincoln. I am doing some research. My research is asking the question: what ideas do healthcare workers have about a person's ability to be a parent? You have been given this letter because you are a parent with a learning disability. Your child is living at home with you.

Please take time to read the Research Information Sheet. If you like you can ask family and friends what they think. You can ask me for a copy of the information on CD if it is easier.

If you are interested, you can tell the staff member who gave you this letter. I will visit you and we can talk about whether or not you want to take part.

Thankyou for taking the time to read this letter.

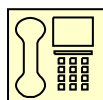
### **Contact for further information:**

If you have any questions about the study, please contact me.



My telephone number is:

01522 886029



Please ask for:

Joanna Rose

## **INFORMATION SHEET FOR PARENT WITH LEARNING DISABILITIES**

**Parents with learning disabilities: assumptions made by mental health professionals about their ability and right to be a parent.**

### **What is the study about?**

My name is Joanna Rose. I am a trainee clinical psychologist at the University of Lincoln.

I would like to find out what it has been like working with healthcare staff when you had a baby.

I will meet with you to ask you some questions about you, your family and the staff that you have worked with. This will help me to find out how you are getting on with staff and how they are helping you. I will record our talk on tape so that later I can listen to it again and remember what we talked about.

### **What will I be asked to do?**

I would like to have a look at your notes to find out about what sort of things you are good at and what you find a bit more difficult.

I would like to meet with you to ask you some questions. This will take about two hours at the most.

Everything will stay confidential. That means that your name and the name of your child will stay secret. If you tell me something that might be putting you, your child or others at risk, then I will talk to you first and then to the staff you work with to see what we can do to help. All the information will be kept in a safe place. The tape of our meeting will be kept for seven years. After that, I will destroy the tape, when I don't need to look at it any more.

### **Do you have to take part?**

You can choose whether you take part or not.

If you decide not to take part in the study, then nothing will change. If you decide that you do want to take part in the study, then also, nothing will change.

If you decide to take part in the study and then change your mind, that is okay too. You can tell me if you change your mind at any time, but if you tell me more than one week after our talk, I might still use some of the things we talked about in the study.

### **What is the goal of the study?**

When I have talked to lots of parents, I will write a report.

I hope that I will find out how we can help parents with a learning disability look after their children, and that I can find out a good way for healthcare staff to work with parents.

### **What will happen next?**

If you say YES to taking part in the study, I will ask you to sign a consent form. A family member or support worker can be with you when you do this.

If you want, I will give you a CD of this information so that you can listen to everything again.

If you change your mind, you can tell me by calling me on the number below. Or you can ask a family member or a support worker to tell me.

### **Who has reviewed the study?**

The study has been checked over by the Leicester Research Ethics Committee. This is a group of people who make sure that research is useful and safe to take part in.

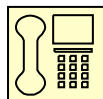
### **Contact for further information:**

If you have any questions about the study, please contact me.



My telephone number is:

01522 886029



Please ask for:

Joanna Rose



## Appendix G – Participant Consent Form



**Trent Doctorate in Clinical  
Psychology**



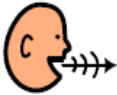




# CONSENT FORM FOR PARENT WITH LEARNING DISABILITIES

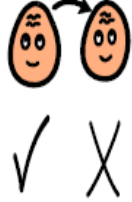


**Title of Project:**

Parents with learning disabilities: Assumptions made by mental health professionals about their ability and right to be a parent.

**Name of Researcher:**

Joanna Rose, Trainee Clinical Psychologist

		Please tick box	
		YES	NO
	Joanna has explained to me about the study		
	I understand the information sheet		
	I understand Joanna may look at my notes		
	I understand that Joanna will talk with me about how I have found being a parent and that our talk will be recorded on a tape		
	I understand that it is my choice to say YES or NO to take part in the study		

	<p>I know that I can change my mind about taking part and can withdraw my data up to two weeks after my interview.</p>		
	<p>Somebody I know was here with me when I signed this form.</p>		
	<p>I agree to take part in this study</p>		

\_\_\_\_\_  
Name of Person with  
Learning Disability

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Participant number:

If you have any questions, please contact:  
Joanna Rose (Trainee Clinical Psychologist)  
Department of Psychology  
University of Lincoln  
LN6 7TS  
Tel: 01522 886029  
Email: 10197388@students.lincoln.ac.uk

This research has been approved by:  
School of Psychology Ethics Committee  
University of Lincoln  
Dr Emile van der Zee (chairman)  
evanderzee@lincoln.ac.uk

Appendix H – Extract from Coded Transcript of Interview with Danielle

	<u>Initial Code</u>	<u>Final Code</u>
Jo: So when all those professionals were involved...		
H1: I think we got too many.	Too many professionals involved	
Jo: Well it sounds like it yeah.		
H1: Especially the social workers, especially when they all tell me something different, me and Tommy, and we still confused we still want to know what they want of us. They all said something different.  First lot they were moaning about the house, then they were moaning about the garden then when my gate broke down they said put the gate like that, we done it like that then the gate fall on top of Leanne and cos we had to go to hospital and they had a go at us {indignantly}.  And we told them it was their fault they told us to put it there. She's been safe in that garden. Oh in the garden I know there's a greenhouse she don't go near the greenhouse.	Lack of Transparency/ Need to be explicit  Constantly Changing Demands from services  Not working together	Unhelpful practice/ Paternalistic treatment  Moving targets  Battle with services
Jo: Does it feel like they were trying to help?		
H1: No they were different what the other social workers saying one was saying something different than the other and we still doing it wrong we're doing with them anyway.  Now we don't. Since Leanne's been in care we don't see them at all we only see them when the meet....a day before...a week before the meeting or sometimes two days before the meeting then we'd see them at the meeting that's all we'd see them. It's the only time we see them.	Changing Targets/ Inconsistency  Professionals unavailable	Moving targets  Unhelpful practice

Jo: So it didn't feel like they were on your side?		
<p>H1: No they still aren't.</p> <p>I don't really like....I don't like this new one I only seen her once. First when that with the old social worker then I seen her in the house. When second one come that's comes why we call her once really and they get us down at the meeting we had a meeting last month and they didn't turn up, she phoned us up said she ill, they get a stand by one said she'd cancelled the meeting and they didn't and we had the lady on there did said Leanne had to do this, Leanne had to do that.</p> <p>I weren't the only one who's unhappy me and Tommy weren't happy so was Sally and Robert. She can't go to playgroups and all that or Brownies and all that. She need one to one. When they first put her in care they was in the wrong care one, they took her in a family one when they shouldn't have done and the second....</p> <p>Mo and Dean [foster carers] doing the same things what me and Tommy were doing.</p>	<p>Not on same side</p> <p>Inconsistent in attending meetings</p> <p>Dictating parenting practice</p> <p>Not satisfied with support</p> <p>Foster parents no better than parents</p>	<p>Battle with services</p> <p>Example of poor practice</p> <p>Paternalistic treatment</p> <p>Dissatisfaction with support</p> <p>Expected to meet higher standards</p>
Jo: Are they friends of yours?		
H1: No they were....they first carers.		
Jo: Oh the carers?		
<p>H1: No the new ones are, we get on better with them Sally and Robert, the old ones Mo and Dean were too strippy. We thought they weren't doing anything with her. They were doing the same things as we were doing.</p> <p>Then we did have at night time some reason the social worker did not....they come and told us two days before Christmas {very indignantly} that we couldn't have her Christmas... Christmas...Christmas...we only can have her between a choice of Christmas Eve, Christmas day or Boxing Day and we picked one and she can't sleep over and they never told us why and we got</p>	<p>Foster parents no better than parents</p> <p>Lack of transparency in decision making</p>	<p>Expected to meet higher standards</p> <p>Lack of transparency</p>

<p>confused and me and Tommy just still don't know why and we asked the social....</p> <p>Then another thing we booked a holiday to go abroad. We booked it, paid for it, they agreed with it. A month before we got due to go they said Leanne couldn't go and social say then it's gonna be hot, too hot for her. That's gonna be too much go on a plane she couldn't listen to noise. Me and Tommy think that she would have enjoyed that holiday in Turkey. Only cos she got a learning difficule and we got a learning difficule she couldn't go.</p> <p>We made arrangements for Tommy's mum to go that would have been me, Tommy, Tommy's mum, Spencer and Kyle we all made arrangements.....and Leanne it would have done. They agreed with that too, they just stopped it a month before and we had to go to the holiday and cancel Leanne, then we're lucky they gave us the money back. They weren't very happy, said it's stupid they're saying disability people can't go on the plane. That's exactly what they said.</p>	<p>Social worker stopped family holiday due to LD</p> <p>Generalisations about people with LD</p>	<p>Discriminative treatment</p> <p>Discriminative treatment</p>
<p>Jo: They said people with learning disabilities can't go on a plane? {Meaning social workers not the Holiday Company or airline}</p>		
<p>H1: Yeah cos that would be too much for her learning difficule. That's what they said to me the social worker did.</p>	<p>Assumptions by social worker</p>	
<p>Jo: Yeah.</p>		
<p>H1: And they sound stupid really. And then they made something of this why she couldn't on the plane and half of that was crap. They said the plane was too noisy, she might break the window, she might not sit on the plane too long and the journey's only four hours, it'll be too hot for her.</p> <p>and me and Tommy wouldn't have let her in the sun too long it's only in Turkey it's not the same hot as this is it was let's say it's mild. Like it was this week we had all that hot. And she would have been in the lakes, the swimming pool and she would have enjoyed that and they had a play in where you go</p>	<p>Making poor excuses to justify decisions</p> <p>Confident in ability to cope</p>	<p>Not internalised assumptions</p>

<p>indoors, an indoors bit, I would have took her in there then if she get too hot I put sun cream take her back to the hotel then I'll go back and out some more sun cream on her then I take for a walk down the town...Turkey town what they call it, sea what they call it and took her on the boat ride I would have done everything she would have enjoyed that and then they told me I couldn't take her at the last moment. Then Tommy went to.....then when she went to Mo and Dean's say she went to you at Disney on a train. They put us on a train to you at Disney I bet we would have gone there with them cos it's a plan and that. She's been to Cornwall with Sally and Robert and I did ask if we can take her one holiday this year..next year and they're gonna let me know and can we have her back two days a night. Waiting for them to come back to us and see if we can.</p> <p>They don't know why they say it's a new social worker don't why things been changed, gonna look at her report and find out why.</p> <p>And I didn't like it when I got a letter the same day when they changed it said I can't have Leanne why should they.....they said to me Oh we have to take Leanne because you got a learning difficules.</p>	<p>Inconsistency of care</p> <p>Received a letter from social services stating child had to be removed due to parental LD</p>	<p>Unhelpful practice</p> <p>Direct experience of assumptions</p>
<p>Jo: They've got to take her into care?</p>		
<p>H1: No they took Leanne in foster care because I've got a learning difficules, cos I've got a disability, it certainly were there in the letter in print, and I got hold of it and teared it, and it actually said, er he said. I weren't very happy about that, I teared it. Should've saved that, they could get done for that, couldn't they? I shoulda kept it. I didn't, I threw it away in a bad mood. They must have a copy.</p>	<p>Claims letter stated child removed due to parental LD</p>	<p>Direct experience of assumptions</p>
<p>Jo: Yeah gosh.</p>		
<p>H1: And that was a bit nasty what nasty what they said that did upset me and I got a temper through it and I signed one Leanne can't go to sleep at</p>	<p>Upset and angered by assumptions</p>	<p>Reaction to assumptions</p>

nights and all that and I've signed it. They break me contract didn't they?	Broken promises	Breakdown of trust
Jo: Yeah. It sounds like for the holiday they were really finding everything they could think of that could go wrong?		
<p>H1: Yeah on the holiday times they want...this social worker wanted to have the contract where we go with someone else with us the contract and we take her out not come in the home we just.....we said no it weren't fair and so did Sally and Robert they say that ain't fair she gotta come home sometime.</p> <p>They wanted us to go out, sometimes with Sally and Robert, we don't mind that, and then have another lady go out with us to the park, go out places in the winter and I said no it wouldn't be fair on Leanne. I don't mind a couple of times, on this, but me and Tommy said we want the help how to look after Leanne properly with our needs and when we ask them they don't answer. Me and Tommy think we're doing the same thing Sally and Robert done and Mo and Dean.</p>	<p>Need to be chaperoned</p> <p>Family want to learn how to cope with daughter's needs rather than be replaced.</p>	<p>Paternalistic treatment?</p> <p>Assumption that parents can't learn?</p>
Jo: Yeah. Why do you think they won't help you with that?		
<p>H1: Well I don't think they would they aint got time. They got too many things.....the last social worker only last for 10 months and then we have a new one.</p> <p>We were a bit worried we had all this care and beyond....bit worried how long Sally and Robert gonna be involved with Leanne. Remember she's gotta leave care when she's eighteen and she's supposed to come home with us. Then we got told a couple months ago off someone that she might not they might put her into a home. And the agreement was when Leanne's eighteen she'd come home. That's what we agreed when we put her first home....when we put her in care, then we find out that she might go to a home where they get someone to come, what they called, someone to look after her and check over. I'm not keen on that idea. They either stay....come home here or stay with Sally and Robert.</p>	<p>Not enough time to help parents learn new skills</p> <p>Concern for future</p> <p>Plans change without consulting parents</p>	<p>Inconsistent Support</p> <p>Parents' voices ignored</p>

Jo: It doesn't sound like they explain things very well to you.		
H1: No they in't explained at all. They aint explained why she went in care and what....and what we're doing wrong with Tommy and them.	No explanations for decisions	Lack of transparency
Jo: Yeah cos it sounds like you're trying pretty hard to do what they want you to do.		
<p>H1: Yeah I am trying to do hard, tidying the house up, doing this, it's a bit messy today I don't had time. They moan about it when it's like this it's gotta be perfect. Anything dangerous they say it's wrong then when you get it next time they say oh you've done it. I say I aint done anything it's the same as it.....it's tidier so that's tidier than it was. It's usually tidy when they come round, really tidy. Today I was late getting up. And they said that's tidy; now they're saying something else change the thing.</p> <p>First they say the house is untidy, now they say oh it's the garden, then they say it's something else you're doing wrong then something else you're doing wrong. They didn't say the different things. Now they say the house is tidier and the garden's done and all that and getting fused {confused} why that is something else is wrong we still don't know what it is.</p>	<p>Required to meet higher standards</p> <p>Can't win/ Moving targets</p>	
Jo: Do you think everybody's house is perfectly tidy?		
H1: No they think you can get the house tidy all the time and I find it won't. Apparently one social worker said to me you've got to have the queen like the..... a house like the palace a posh....or the show house you know where you look round someone's show house. And what about the decorating social worker said to me can't have this on the floor and you can't have that, I used to tidy it up before Leanne come home and do the housework every two days, miss one day and one do the next day. Poor Tommy his feet's been hurt his feet's been playing up, can't do much I have to keep in and out making cups of tea, to help him walk to the toilet and everything it's a bit hard.	Required to meet higher standards	



Jo: It sounds like they want you to be better than everybody else not the same?		
<p>H1: Yeah that's what I feel like. Really don't want the house like a show house. I got a Saturday....one day we asked them how do you want the house to be like and of them said I like the house bit like a show house. I couldn't make the house like a show but give me the money I would. Painting and decorating they do it all decorating and all that.</p> <p>They want us to get a cleaner to come round and pay for it once a month and look out for the cleaner come I do it myself. He house is a bit better than it used to be.</p>	<p>Required to meet higher standards</p> <p>Unrealistic demands</p>	
Jo: Why do you think they ask so much of you?		
H1: Cos I got a learning difficule and they reckon I couldn't cope with Leanne with her needs and they said I could cope with the other two. What's the difference? Then I want to ask them what happens if I try for another baby? Oh we can't do anything only if they can't do anything but that's nothing to do with them. They said I can have one except they reckon I'm too old. At 46 you could get a, what's it called Mongol baby would they say?	Set unrealistic targets due to LD	<p>Expectation of assumptions</p> <p>Treated differently due to LD</p>
Jo: Oh Down's Syndrome.		
H1: Yeah I think I'm 46, 47.		
Jo: So it sounds like they are asking you to do things so perfectly almost to prove that you can't do it? Is that right?		
<p>H1: That's what it feel like to me. When you done it right you don't get praise when you doing something wrong they put it in their report.</p> <p>We done something really good there we put a gate...we put up their thing for them and they never put the report when we done the gate. They put all bad things about us and never did put any good things about us and all that. You know they complained about the gate with Leanne falling and we come back</p>	<p>Set targets to trip parents up</p> <p>Ignore positives and focus on negatives</p>	<p>Perceived discriminative treatment</p> <p>Professionals seeking to confirm their assumptions</p>

<p>and got my brother-in-law and Tommy put a gate up straight the next day.</p> <p>They did kick up that's like once they accused me and husband.....Leanne got hold of this carrot, a toy carrot and the school come and she stick it out of her bum. And the school put her to social worker called Tommy child molester then. Took her to the doctors and they said no Tommy aint doing it she doing it.....they took her home with the carrot and they saw her doing it. The social worker got told off then from the doctor. The doctor said don't be stupid it's a carrot, the school got told off for giving her a carrot. She sticking it out of her bum, a carrot and they thought Tommy was doing it and it weren't.</p>	Accusation of guilt	Behaviour based on assumptions
<p>Jo: When you first decided to have a baby did you think what other people would think?</p>		
<p>H1: Yes I thought I was doing okay when I first had a baby. For the first three months till the house person opened her mouth, well I didn't really like her, I didn't get on with her, I thought she was a bit snobbish she weren't even helping me at all.</p>	Status of professionals	Power imbalance
<p>Jo: Who was that sorry?</p>		
<p>H1: The house man....the house visitor.</p>		
<p>Jo: Oh yeah the midwife.</p>		
<p>H1: The midwife I don't think she was very good of me twice. Cos when you want to see them they never turned....she never was there. When you get weighed cos she was losing weight they thought it was us doing it, weren't feeding her properly. Then we found that she'd got that illness we were.</p>	Professionals unavailable	Unhelpful practice
<p>Jo: And what did you think other people would think about you having a baby?</p>		
<p>H1: They would probably think I wouldn't cope they were surprised when I did cope a little....better than they thought it was they all said.</p> <p>Sometimes I wish I'd done the routine different cos I got routines.....when you got two kids you have to do the routines cos one had one routine then the other. They all think you got to have the same routine for all three and you</p>	People made assumptions but proved them wrong	Assumption of inability to cope

can't cos me oldest boy Dave was different to the other two. And it was hard to feed one baby and then feed the other cos one was only 9 months old and one was....one born February, one born April.		
Jo: Oh so really close together?		
H1: Yeah 99 and 2000 and it was hard.		
Jo: So when you thought that other people would think that you couldn't do it did that affect you?		
H1: Yes and I thought I couldn't do it and that's the reason I got put off a little bit and thought I couldn't cope myself. Now I think.....now I could if I have another one I think cos only got John Lewis. Put off my neighbours cos I got two boys I'd like to have another little girl. Not just for Leanne say.... not cause Leanne go in care or anything I always wanted like another little girl. I'd like to call her Sophie so I have done. That's what we just agreed Tommy called her Leanne and I wanted Sophie.	Internalised other people's assumptions	Self-stigmatisation
Jo: So it made you think that you couldn't do it. Do you think that affected your confidence a bit?		
H1: Yes to couple years to Leanne went care that do getting me confidence low. Feel like Leanne weren't my daughter when she went....  Honestly I still think they forced me take her in care. I know it's voluntary but still think they blackmailed me they said if you don't take her into voluntary care we'll take you to court and you won't see her at all. That was sort of blackmailing. We didn't want to go through the court thing and all that.	Decreased confidence/ not feeling like a mum  Felt forced into decision by threat of court proceedings	Emotional impact of assumptions  Power imbalance/ powerless to fight services
Jo: Did you think professionals would treat you the same way as everybody else?		
H1: No. I was getting con fed up.....still getting fed up with them the social workers come there be only for 10 months get rich and then they changed it. Most we had lady social worker I only had two men. This one, her new one,		

only met her twice who don't called Kay. She did dick down the other social worker she said to them we have that little gate off and with the fence up she said we don't need both. She told that other social worker you don't need both. We done that both up now and we keep the big gate shut when Leanne come home but for the garden we leave it open when she's not there.	Professional inconsistency	Unhelpful practice
Jo: So why did you think that they'd treat you differently?		
H1: Cos I got a learning difficule and Tommy's deaf isn't he and I can't do two things.....I'm not a person you know one could two things at a time. Cos we're got learning....and we can't read and write and we have help to read and write think they treat you differently because of that and I think they think we're stupid me and Tommy.	Treated differently due to LD	Treated differently
Jo: They think you're stupid?		
H1: Yeah that's what I feel.		
Jo: What other guesses do you think they've made about you because you've got a learning disability?		
H1: That we couldn't cope with Leanne her needs. That if she had periods and all... I think I could have done. They didn't give me a chance to do it. She promised me she got all her pads now. She had 3 periods she don't have then regularly she's have them.... miss a month and have a month I think. I think I could go.....only thing I just told you she had problem with sanitary towel she won't keep them on. Then you get used to that if I had more practice I could have done it all. Would've learned. I thought I would have got on okay with her. Her needs and all that.	Assumed they couldn't cope without offering chance  Confidence in own ability to learn	Assumption of inability to cope
Jo: So you thought you'd be able to learn what you needed to do really? You think they thought you couldn't learn?		
H1: Yeah that's what I feel like they couldn't.....that's why she won't care for her needs when she grown up like her periods and her need to take whole load tablets which she aint gonna take now because she's grown up. And she's	Assumption – inability to learn	Assumption – inability to learn

grown up like a proper little madam and cos if she was talking she wouldn't of gone in care cos she couldn't talk they put her in care they thought.....they thought cos she couldn't....that's what they thought ..they feeling they think she got her feelings so people they know her feelings. And I don't think the first carers I don't think she was very happy.		
Jo: So you thought that they'd think that couldn't do it and you wouldn't be able to learn?		
H1: Yeah.		
Jo: Did you think they'd make any guesses about what your children would be like because you've got learning disabilities?		
<p>H1: Yes that's what I feel like they did. If they say we can't cope why they aint took the other two away. John Lewis he's got learning difficules now he just....I told you about his growing cos he can talk they wouldn't touch him.</p> <p>Leanne can't talk if she was talking we think they would not touched her. That was easy thing for her to take cos she was let me say learning difficule and she can't talk and then she got that illness they thought it's easy we'll take her and they took her in care. I think they should kept how it was respite. Three days a week we'll get on alright cos her nanny's name was Leanne she getting alright with her. Everything go Leanne then all of a sudden a social worker we didn't like we won't mention her we didn't like her said we not going okay that was. We had one incident this is true Leanne staying at Leanne's caters, respite carer the respite carer Leanne as well.</p>	<p>Unjustified assumptions</p> <p>Used daughter's health problem as excuse to take her away</p>	<p>Services want to remove children</p>
H1: I think they guessed that Leanne gonna be and John Lewis gonna be like me. I forgotten what we say now.	Children will be 'like me'	Assumption – children will have LD too
Jo: How like you what do you mean?		
H1: I think they think they're gonna have learning difficule like me and be stupid and I don't think they know more than that. And I saying Leanne can't talk and they...that's why they took her into care. I still think if she was talking she wouldn't have gone in.		Assumption – children will have LD too

## Appendix I – Example of collated extracts for themes of ‘Assumption of inability to cope’ and ‘Accusation of guilt’

(Each different colour represents a different participant)

Assumption - unable to cope with children			
Jo:	Ok. Do you think, not thinking back, but just your best guess about what it's like now, do you think professionals treat parents with learning disabilities the same as other people?		
PC:	Not really, it's different, innit?	Treated differently due to LD	
Jo:	Yeah, what's different about it?		Expectation of assumptions
PC:	Things are, because people who've got a learning disability, they can cope, but people who ain't got a learning disability, they think sort of they can't cope.	Assume people with LD can't cope	
Jo:	Ok, and how have you found working with Callie [Social worker]?		
PC:	She's alright in small doses, but she thought we couldn't cope most probably.	Social worker thought they couldn't cope	Experience of assumptions
Jo:	Oh ok, did you think some people would think that you couldn't cope?		
PC:	Yeah, most probably	People would think they couldn't cope	
Jo:	Yeah? Like who?		
PC:	Social services and all that.	Social services would assume they couldn't cope	Assumptions about assumptions
Jo:	What do you think they think about people with learning disabilities as parents?		
PI:	Well if you're talking about social service I think they might think you shouldn't have kids at all for one reason they think that you can't cope.	Think you shouldn't have kids Think you can't cope	Expectation of assumptions
Yeah, oh yeah, yeah, yeah erm yeah because we said how like their disability could be worse than mine and then we've like, their child could be even worse. Or just thinking of those terms but no, they've never like said just cos I've got a disability would I be able to cope with Samuel with a disability. But that's never occurred because we do our best with Samuel, and even though I've got a disability as well that's never been an issue, no		Might assume parent with LD wouldn't cope	No experience of assumptions
Jo:	And why do you think that is, what do you think they're worried about? What do you think they're assuming about you?		
PB:	Well they're assuming that obviously we can't cope with him, which is...	Assumption that parents can't cope	Expectation of assumptions

## Assumption - unable to cope with children

You know, mum said they said 'Oh, we don't think Greg can cope looking after him' so we were getting recommend he be staying with her but I got this place.		And that he couldn't look after a child	
Jo: What did you think they'd think?			
PF1: They'd think I wouldn't be able to do it and they think I'd have me kids into care. Yeah which is a normal thing.	Family assumed she couldn't do it and kids would be taken into care	Experience of assumptions	
Jo: And why did she [Social worker] think that you couldn't?			
PE: I don't know why. I don't know. I think said I was too early to have one.			
Jo: Okay. Was it because of your learning disability do you think?			
PE: I think so yeah, yeah.	Thought she could cope due to LD	Expectation of assumptions	
Jo: Do you think they [professionals] make guesses about people with learning disabilities?			
PF1: Yeah say they're not careful looking after children and an awful while that I was and you know.	Assume parents with LD are not careful looking after children	Expectation of assumptions	
Jo: What other guesses do you think they've made about you because you've got a learning disability?			
H1: That we couldn't cope with Leanne her needs. That if she had periods and all... I think I could have done. They didn't give me a chance to do it. Then you get used to that if I had more practice I could have done it all. Would've learned. I thought I would have got on okay with her. Her needs and all that.	Assumed they couldn't cope without offering chance		



## Accusation of Guilt

	Every day and every time, when we... rang up and said I couldn't see her, so we ran over every time to... on a tape and they taped it, so they know what we were saying, they give it to the social worker and I say that's why they took her away from us,	Made to feel like criminals
	I don't know, they just blamed me and so they took us away from us. They didn't tell us that she'd been adopted.	Assumption of risk
PA:	I don't know, they just blamed me and so they took us away from us. They didn't tell us that she'd been adopted.	Child removed due to mistaken blame
	then you got other people outside phoning up and saying that they'd seen my daughter outside the back garden with nothing on this and that and they're all a load of lies cos that day they say they have [seen her] she's in care, well not in care foster care or respite whatever they wanna call it	Social services were immediately concerned about all the children
	Because I had a learning disability they took my other half's side because he was actually the worker at this point and he said something to the care team saying that the children smelled going to school and somebody's reported it from school and the other things on top of that when I explained and it just doesn't look very good on my behalf when the other people are slagging me out cos it just looks as if you're a piece of muck	Quick to believe reports due to LD
	He accused me about three times hitting him. I had to stay in jail for a day	Assumed to be guilty
	And when at first they thought I wasn't feeding Leanne very good cos she weren't putting on weight. I was feeding her feed she was having six meals a day. She was eating...she used to be a..she eat a lot.	Assumed neglect rather than unavoidable problem
	They all blamed me that wasn't me that was Tommy's dad he left the glue out and me oldest boy got hold of it and put it on Spencer's hair and they came round to see Kyle I think it was, no I don't think it was they came to see if I was Okay. Tommy's dad left the glue out. He put it up on the top wardrobe and didn't throw it away when he should of done. I don't think we would have had social worker then. One of the problems.	Blamed for other people's mistake
	They did kick up that's like once they accused me and husband.....Kate got hold of this carrot, a toy carrot that the school gave her and she stick it up her bum. And the school put her... the social worker called Tommy child molester then. Took her to the doctors and they said no Tommy aint doing it she doing it....they saw her holding the carrot and they saw her doing it. The social worker got told off then from the doctor.	Jump to conclusions of abuse